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ABSTRACT

This report describes the activities and outcomes of Project RISK, a 3+2 years service delivery demonstration and replication project that was based on the assumption that infants of HIV positive women are at significant developmental risk from prenatal exposure to HIV infection and, possibly, teratogenic drugs, as well as from the complex caregiving environments of families with HIV. Project Risk attempted to facilitate the transition of developmental and family coordination services from tertiary AIDS centers to community early intervention services. There were three components to the RISK model: (1) direct service to assess developmental status, risk, and needs for children and families and to provide support and intervention in the community for children referred to tertiary care hospitals for "exposed not infected" status; (2) to develop a model for providing linkage to community service agencies appropriate for child and family needs; and (3) to provide education in pediatric HIV risk and infection and associated developmental and family needs to community service agencies. Materials include a study on the community service utilization of families of young children who are exposed to HIV and a directory of service for individuals and families living with HIV/AIDS in Wake County, North Carolina. (CR)

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ED 432 113

Multiple Risk Associated with Prenatal HIV Exposure: An Interagency, Community-Focused Demonstration (Project RISK)

Final Report
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I. EXECUTIVE SUMMARY *(2 pages)*

Project RISK was a 3+2 years service delivery demonstration and replication project, the design of which was based on the assumption that infants of HIV positive women are at significant developmental risk from prenatal exposure to HIV infection and, possibly, teratogenic drugs as well as from the complex caregiving environments of families with HIV: including poverty, the over-representation of minorities, parental substance abuse, poor supports from extended family and community, and sick or deceased family members. Early intervention for these HIV exposed infants requires recognition of their risk status, then family focused, culturally competent, interdisciplinary, interagency, community-based approaches. Most are identified and can be served initially at tertiary care hospitals, where state-of-the-art diagnostic testing and clinical trials for new drug therapies are available. Too often, the HIV exposed and found to be not-infected infant is discharged from the tertiary hospital without assessment of his/her high risk status and without critical transition to community tracking and intervention services. Project RISK was directed at facilitating the transition of developmental and family coordination services from tertiary AIDS centers to community Part H services for which they are eligible by their high risk status.

There were three components to the RISK model: direct service, community linkage, and community provider education, developed and implemented at the original (Duke University Medical Center; Phase I) site and at 2 replication sites (Phase II). The components are described below.

Direct service and needs assessment. During Phase 1, Project RISK identified a sample of 43 young infants (<3 months of age) and their families seen in the context of Duke's Pediatric AIDS clinic for Indeterminate HIV infection due to known maternal infection during pregnancy. Direct services, including multi- and interdisciplinary assessments of infant development, family functioning, and family support needs, were conducted through the Duke clinic from referral to discharge for those demonstrated to be not-HIV infected. The results included the increased awareness of the high risk status of these infants and an increase in referrals to North Carolina's high risk tracking and screening system, Child Services Coordination. The assessment of child and family needs for these HIV Indeterminate infants continue after the Project RISK grant funding, and children are consistently referred to community Part H services by the hospital team before discharge from the clinic.

During Phase 2, Project RISK was designed to identify infants seen for Indeterminate HIV infection in 2 additional tertiary hospital treating Pediatric HIV/AIDS in North Carolina. The goal was to recruit 20 infants and their families in each site. Sixteen were successfully recruited and followed at N.C. Baptist Hospital, and the model was continued there when grant funding ended. The second site, East Carolina University (ECU), 20 infants and families were recruited and followed with some disruption when the primary collaborator at that site left her position. The data from the second site are incomplete but informative, although the model was not successfully replicated at ECU in

that the model is not continued. Toward the end of year 4 of 5, a third site, Carolinas Medical Center in Charlotte, volunteered to participate in components of Project RISK; and information about the developmental and family needs of 6 additional children was obtained there.

Community linkage. Linkage with community services were initiated during Phase 1 and facilitated through the existing community-based consortia established to address Part H of P.L. 99-457 and through the Ryan White consortia established for persons with AIDS. The overall goal of the first phase was to have accomplished integrated community care for the infant and family within one year after the initial referral to the Duke team and before discharge from the clinic. Now, 6 years after the Project RISK implementation at Duke, all HIV Indeterminate children are assessed in terms of behavioral and developmental needs; children for whom there are developmental and/or family needs are referred to Child Services Coordination, the community Part H system for children from birth to three years.

Community linkage at replication sites. Linkages to the community Part H services were successful in both replication sites, especially at the N.C. Baptist Hospital site with 81% children participating in Project RISK successfully referred to Child Services Coordination there. The most successful replication occurred at this site, where the community-based eligibility assessment for high risk infants now occurs in the hospital clinic. Once per month a Child Services Coordinator from the community agency attends clinic and provides the needed eligibility assessment for all children between 6 and 12 months of age. In this way, transition is completed in an optimal way; and the child is in the community services system well before hospital discharge. This replication of Project RISK here provides a state and national model for addressing the transition of this group of children and families from hospital to community.

Community provider education. As community linkages were formed during Phases 1 and 2, it became apparent that providers were in need of education surrounding the needs of families caring for HIV-exposed children. In addition, it also became apparent (and verified through a statewide phone interview; see Evaluation section) that the primary need in the communities was for linkages between child service providers and adult service providers. All communities have child services coordinating councils per Part H requirements; unfortunately, no community had a system for adult and child services providers to communicate about family needs. Therefore, early into the implementation of Project RISK, the educational component became a community meeting for adult and child providers. These lunch meetings included specific education about HIV in children, but they were primarily designed to address the gaps between these groups of providers. The community meeting was developed to bring service providers together as a forum to share information about the needs of families as well as facilitate linkages among professionals in the community.

II. GOALS, OBJECTIVES, AND ACTIVITIES

The primary goal of Project RISK was to facilitate the transition of developmental and family coordination services for HIV exposed children from tertiary care hospitals to their communities. Three components were developed to demonstrate the service delivery model: direct service, community linkage, and community service provider education. The original goals of each component were:

Component 1: Direct Service

To assess developmental status, risk, and needs for child and family and provide support and intervention in the community for children referred to tertiary care hospitals for "exposed not infected" (EN1) status.

Component 2: Linkage

To develop a model for providing linkage to community service agencies appropriate for child and family needs as identified in component 1.

Component 3: Education

To provide education in pediatric HIV risk and infection and associated developmental and family needs to community service agencies identified through component 2.

The project was designed to demonstrate a model for Pediatric clinics in tertiary care hospitals, often the first referral point for HIV seropositive children and their families, to establish linkage and support for accessing family centered community based care in the areas of child development, family needs and support, and substance abuse treatment for parents. The RISK model is family centered in that families/caregivers collaborate in the assessment process by identifying and prioritizing their own needs. The result of the assessment, the Community Family Service Plan (CFSP), is seen as a contract among the family, the Duke team, and the community agencies.

Children and families are targeted at referral to the hospital clinics and assessed during their health care visits in these three areas of service needs. As community linkage is forged and integration of services facilitated, educational needs for community service providers are assessed. When feasible, training is facilitated by the Part H and Ryan White consortia locally in order to empower community groups and to avoid redundancy in training efforts. These educational opportunities are also provided in an interagency manner to facilitate further integrated care for child and family at a local level.

Original project objectives are listed in *italics* and the Phase 1, primary site, outcomes are discussed briefly below. A discussion of the three components during the replication phase (Phase 2) follow.

Objective 1. Identify n=60 infants referred to the Duke Pediatric Infectious Diseases team at Duke for their EN-1 status, that is, Indeterminate HIV, to participate with their families in demonstrating the effectiveness of Project RISK.

Outcomes/comments. Forty-three HIV-exposed infants were recruited into Project RISK at the original site, Duke University. At the suggestion of the grant proposal reviewers, the records of similar children, seen at Duke prior to Project RISK, were reviewed to determine needs and referral patterns identified in the clinics before the implementation of Project RISK. The results of these assessments, including the "pilot" data, results from the primary Duke site, and results from the replication sites are in the Evaluation section.

Objective 2. Develop a multidisciplinary assessment package designed to result in Child and Family Services Plan to be used for transition to local community case management and services.

Outcomes/comments. The multidisciplinary assessment package (see appended materials) was developed and used at Duke and, later, at the 3 replication sites. As a part of the evaluation for the project, the usability of the package was assessed by the

replication sites; and only a portion of the assessment package will continue in use after grant funding and evaluation activities have ceased (July 1, 1999).

The transition to local community services was facilitated by 1) referrals to the Part H provider in the community (with parental consent) and 2) the use of a child community "Passport". The Passport is an individualized information brochure prepared for the family at the time of hospital discharge about community service providers that are or may be needed by the family. The replication sites used the Passports with their clients as well (for sample Passport, see appended materials).

Objective 3. Develop a linkage system for each of the communities targeted by the inclusion of a child from the area in the initial sample. In North Carolina, the primary linkages are with the state Part H Child Service Coordinators and the Ryan White HIV Care Consortia. These are the first contacts for linking a child to services and to tracking and also for determining community training needs.

Outcomes/comments. A major outcome of the 5 years of Project RISK was determining the best way to facilitate the initial linkage between hospital and community and identifying strategies for making the community referrals acceptable to and utilized by the families. Child linkage to community agencies prior to hospital discharge, particularly North Carolina's Part H Child Services Coordination (CSC) System, was accomplished at the primary (Duke site) by referral and ongoing communication between clinic staff and the CSC providers. Prior to Project RISK, the only referrals made to community CSC were those for children with documented developmental delays and obvious need for early intervention. Through Project RISK activities, there was an increased awareness of the tracking and case management roles served by the CSC system, and referrals by discharge have become a regular practice. As a related outcome, the relationships between Duke

team staff and community providers became stronger; often CSC providers attend clinic with their clients.

However, at the primary site, it was documented that a service delivery gap could still occur when the referral was not successful--- due to poor family compliance with home visits, lack of persistence from the CSC, family fear of violations of confidentiality in the community, and so forth. In these cases, the children involved could be lost to follow-up after discharge from the hospital clinic. At one of the replication sites, the gap was addressed best by establishing a role for the community CSC in the clinic itself. At the replication site in Winston-Salem, children eligible for CSC tracking and intervention are identified in the clinic; with parental consent, the state agency representative provides an entry level assessment on site, and (subsequently) the child is entered into the system, and a relationship between community provider and family is accomplished. The family is able to transition more easily from a known and trusted system (clinic staff) to a new one. At that site, many fewer children are lost to tracking and to services in the community. This model is an exceptional outcome of Project RISK and provides an important component for the outreach model for other tertiary care and community settings.

In terms of linkages among agencies within communities, Project RISK initially addressed the state level administrations for both Ryan White and the Part H Coordinators. In this regard, Project RISK staff made state-wide presentations regarding the multiple needs of children and families affected by HIV/AIDS. However, it became evident that training and coordination needed to occur at the local level, that information at "train the trainer" conferences was not getting to the local provider. To that end, we developed the "community meeting". (The meetings are described in depth under

Objective 4). The community-based meeting created the opportunity for child and adult providers who are likely to serve HIV-affected children and families to come together to exchange information about their services. As our evaluation of these meetings indicates (see Objective 4), the interagency contact and the information exchanged was very important.

Objective 4. Assess communities' needs for the education and consultation necessary to accept care and case management of children with or at risk for HIV/AIDS and their families that can include caregivers with HIV/AIDS. Provide the opportunity for community providers from different adult or child oriented agencies to meet one another and establish linkages.

Outcomes/comments. Community needs were assessed by a systematic needs assessment of communities in North Carolina who (at the time of the survey) had children receiving health care at the primary site, the Duke clinic (whether community providers were aware of that child and his/her HIV status or not). Project RISK developed for each community an interagency list of adult and child service providers who could potentially be involved in providing services for this population. Persons from these groups participated in telephone interviews individually to determine their current contact with families with HIV/AIDS, their knowledge of other agencies, their specific needs for training, and their perceptions of community barriers. The results of the interview study are present in the Evaluation section.

The list of people interviewed in each county served as a springboard for developing a larger list of child and adult service providers to attend the community networking meetings. These meetings were designed to provide education about HIV/AIDS and to facilitate linkages between community agencies in an attempt to coordinate systems of care within the community for children and parents affected by

HIV/AIDS. The community meeting involved a 2 1/2 hour meeting for approximately 30-60 individuals; the meeting included a lunch as an added incentive and to provide the opportunity for informal networking. (Community meetings were held at replication sites as well. See Objective 6.)

The agenda of the community meetings included: informal networking, presentation of the current epidemiology of Pediatric HIV/AIDS (including the numbers of exposed and not infected children), education regarding current therapies for the child with HIV infection, presentation of provider survey results, and the introduction of local services represented. The introduction of the service agencies attending the meeting was facilitated by a case presentation-- to which each provider responder in terms of the range of services available from the agency as well as their perceptions of other referral needs for the child and family. Meeting participants left with a detailed listing of the meeting participants and the services they can provide to children and families. The handout of community providers evolved from formal, bound lists of providers available after the meeting to more informal computer generated lists available during the meeting to be used to add/change information. The latter model proved to be more effective. The use of the meeting roster was extremely helpful to participants since formal resource directories are quickly outdated. An example of an (early) community provider booklet and a page from the (later) roster to be used during the meetings are appended.

Importantly, the participants included known agencies, e.g., mental health and also little known groups, e.g., churches that provide shelter or clothes to needy families. Each meeting included from 30 to 60 individuals, representing 15 to 25 agencies or groups. This perturbation of the original RISK plan for community education, informed by the

formative evaluation of our original design, was tremendously successful and lends itself to further outreach activities during the next several years. The reception was extremely positive and emphasized, in particular, the need for and ignorance of existing HIV case managers in the health departments and the HIV consortia. A total of 11 meetings in the primary and replication sites covered the following counties in North Carolina: Guilford, Davidson, Forsyth, Rowan, Surry, Wake, Durham, Orange, Vance/Granville, Pitt.

Objective 5. Increase knowledge of resources and services of child and adult providers likely to serve HIV-affected children.

During project implementation, objective 5 was addressed by several activities, including an (unproposed) survey of adult and child providers in communities identified because each had at least one child being seen at Duke for HIV exposure. The results of the telephone interview of providers indicated that the major barrier in communities was not HIV/AIDS education per se but rather a rather dramatic lack of information about child providers on the part of adult service areas and an equal lack of information about adult service providers on the part of child providers. We were surprised to discover that early interventionists did not even know that in North Carolina mental health services have women's substance abuse coordinators; they were not linking mothers with substance abuse disorders to needed services. In most cases, adult substance abuse counselors had never heard of the Child Services Coordination System in North Carolina; therefore, the children of women with substance abuse disorders and HIV/AIDS were not referred to the state's system for tracking and screening for special needs. Almost no one, adult and child providers alike, knew about the resources available to families from the AIDS Consortia or Service Agency in the community.

The survey findings, further elaborated in the Evaluation section, led to the primary intervention for Objective 5: the community services meeting for adult, child, and family providers. The meetings were designed to include health, mental health, AIDS consortia and service agencies, early interventionists, CSC's, AIDS case managers, eligibility workers, and so forth in each community as well as those agencies that may only be available to some: Make a Wish, church groups, and so forth. We learned that, possibly as a result of the Part H mandate for interagency groups, community providers believe that there is interagency communication in their areas. The meetings proved that they were as surprised as we how many groups available to help their families were not previously known to them. Importantly, this situation seemed to be more the case for child providers; we concluded that the mandate of the IFSP for birth to 3 providers may result in the sense that they (CSC and early intervention groups) should/must/can address all family needs. Paradoxically, this mandate to address the family as a whole may actually, in some cases, provide a subtle barrier to community services access and utilization for families with multiple and diverse needs.

Objective 6. Develop a mechanism to share information with providers and families about current and new services.

The community meetings also provided the primary forum for dissemination of information about Pediatric HIV/AIDS, current diagnostic strategies, current therapies, and the multiple and diverse needs of families. As noted above, the educational agenda emphasized the epidemiology of Pediatric HIV with special updated information about transmission rates, interventions during pregnancy to prevent transmission, and the (resulting) large number of children who are HIV-exposed, living in families living with

HIV/AIDS, but who themselves are not infected. The fastest growing population of new HIV diagnoses is in heterosexual women in the rural South (data from the Center for Disease Control, 1996) and, with the intervention of antiretroviral therapies during pregnancy, the rate of transmission to the child has been reduced from approximately 25% to approximately 6% (data from the Pediatric AIDS Clinical Trial #076 and subsequent studies). The number of children who are HIV exposed, antiretroviral therapy exposed during pregnancy and are affected by family HIV/AIDS is rapidly growing. In these interagency meetings, the case is made for the multiple risks and needs of these children and their families. Copies of some of the slides used for these presentations can be found in the appended materials.

Objective 7. Prepare for dissemination to other settings the three-component model for transition from tertiary center to community services for the child and their families.

Dissemination included a) replication in other communities and hospital settings and b) strategies toward dissemination of the model beyond the immediate North Carolina network for care of children with or exposed to HIV/AIDS.

a) Replication of the model during the last 2 years of the funding

Replication activities were designed for two settings and was completed in part in three settings. The full model was realized in one of these settings. The essential components of the model to be replicated included:

Component 1- Multidisciplinary assessment of child and family needs to include training in strategies used in the original demonstration.

Implementation. Each site tailored the original Project RISK measures to best fit the needs of their families and the multidisciplinary team. At each site, the primary family

needs assessment was accomplished by the team social worker through collaboration with the team's lead physician. Formal child development assessments of replication cite RISK children were performed on a monthly basis by Dr. O'Donnell, Project Director. She also used the time at the replication sites to make connections with child development specialists at those sites, who will be able to provide developmental assessments for these children after Department of Education funding has ceased. This was particularly successful at one site, N.C. Baptist Hospital; and there, the developmental assessments continue through the collaboration of the state-run community agency, the Developmental Evaluation Center.

Project RISK coordinator and director, Drs. Fair and O'Donnell provided technical assistance to the sites for presentations at the second annual conference on Psychosocial Issues of Pediatric AIDS held on March 11-12, 1997. In addition, all replication site personnel attended semi-annual training and consultation meetings at Duke; on these occasions, specific assessment, referral, and community linkage issues are barriers were discussed. Specific training for these Pediatric HIV/AIDS health providers in the area of substance abuse was requested took place at the North Carolina-Children's AIDS Network's (NC-CAN) quarterly social work training in June, 1997 (provided by Dr. O'Donnell and J. Georgi; in addition, further training on the effects of HIV on child development was presented to the same group in June, 1998. Follow up substance abuse training occurred on May 29, 1998; all Project RISK original site and replication personnel attended the full-day training led by Jeff Georgi.

Component 2- Transition of case management to the community by the time of the child's clinic discharge, included

a) *Translation of the multidisciplinary assessment into a Community Family Service Plan;*

b) *Preparation of family passport to community services; and*

c) *Transition of the (Medicaid-eligible) case management responsibilities from the hospital social worker to the local (Part H) Child Services Coordinator in a case coordination/IFSP meeting with the family.*

To date, all of the replication site Project RISK children have "graduated" from the clinics. The groundwork was laid to translate the multidisciplinary assessment into a Community Family Service Plan for the communities' Child Services Coordinator. All graduates received an individualized "Passport" to community resources.

In collaboration with the Duke RISK staff, the site replication social workers received training regarding the IFSP process or the CFSP as it was called in Project RISK. While they were not responsible for actually writing the IFSP, their assessment of the child/family contributes to (and avoids redundant assessments) the community providers doing so. Additionally, they already have access to and an established relationship with the family. All too often the transition to community services falls apart because families do not know/trust the community provider after the strong bond forged with the tertiary care social worker. The social workers facilitated the community transition by introducing the family to the Child Service Coordinator and demonstrating that she trusts the Coordinator who can address their needs competently and confidentially. Specific information about referral needs is communicated in this transition, obviously best in person as occurs in the Winston-Salem replication site.

Component 3- Facilitation of integrated services and education in referral counties.

The replication sites were assisted in creating the community meetings demonstrated in the original project for counties with children and families being served at the tertiary care center. It is important to note that not all communities knew that they had children and families in care for HIV/AIDS, but the communities were invited to participate in the process for identifying and integrating services nonetheless.

For the community meetings for Baptist Medical and ECU, their hospital clinic staff received technical assistance during the preparatory phase and had Duke RISK staff at each meeting. These meetings facilitated the transition of children from the tertiary care center to the community since all of the community providers were gathered to discuss issues pertinent to the HIV-exposed child and family. Special collaboration with the local HIV Consortia, HIV case manager, and Child Services Coordinator in arranging and facilitating these meetings was established. When possible, parents and caregivers were included in the community meetings as special consultants about service delivery needs and activation.

b) Further dissemination of the model

In terms of the RISK model for transition from hospital to community, activities for dissemination of the model and outcomes are planned. First, the full model was manifest best at the Winston-Salem site. Drs. O'Donnell and Woods (Pediatric Infectious Disease Physician at NC Baptist Hospital) are planning to describe the model in the North Carolina Pediatric Association Newsletter later this year and possibly present at the annual meetings of the North Carolina Pediatric Association.

The replication team at N.C. Baptist is considering ways to provide outreach to other settings about the model as implemented in Winston-Salem (in particular). In these plans, the need to also include primary care Pediatricians in educational opportunities is emphasized. Possible funding from the American Academy of Pediatrics is being explored.

III. THE CONCEPTUAL FRAMEWORK FOR PROJECT RISK

Public Law 99-457 introduced a new era of federal commitment to appropriate and family centered services for young children with or at risk for developmental disabilities. State incentives to implement these services notwithstanding, the provision of developmental and family care for children with HIV infection or exposed to maternal HIV has lagged behind other priorities. Barriers to services for these children with multiple risk include the still evolving knowledge of HIV disease, fears associated with an infectious disease, limited data on the associated developmental dysfunction, and the seeming overwhelming needs of families and communities caring for families with HIV/AIDS.

The model for demonstration during Project RISK is based on a conceptual framework derived from several areas of research and practice. Each is briefly discussed; the primary thesis is emphasized.

Epidemiology of Pediatric HIV/AIDS. The primary risk for HIV disease in children is maternal transmission Infants of HIV infected women are considered indeterminate (or EN1) until the presence or absence of the HIV is diagnosed. When Project RISK was first proposed, accurate diagnosis was possible by 6 to 18 months of

age. Currently, newer diagnostic methods make diagnosis by 3 months of age 90% accurate. When Project RISK was first proposed, approximately 1 of 3 infants of women with HIV disease would be infected themselves. Currently, new prophylactic methods, using antiretroviral drugs during pregnancy, have reduced the transmission likelihood to 6 to 8 percent. These data indicate that at least 92 of 100 infants born to women with HIV disease will not be infected. The numbers of these exposed and not infected children are growing also because the greatest incidence of new HIV acquisition is in heterosexual women, most of whom are in their childbearing years. Project RISK was designed to focus on this large and growing group of children who heretofore have been lost to community service systems.

Developmental disabilities with HIV disease and the multiple risks associated with HIV in the family. Adult and child studies document the evidence of HIV in the central nervous system (CNS) and its neuropsychological manifestations. As many as 75% of untreated children with HIV demonstrate some developmental disabilities. Animal studies as well as postmortem human studies demonstrate the effect of HIV on the developing central nervous system. However, results in some few studies of not infected children of HIV infected women suggest that developmental risk is present even without viral transmission. Project RISK was designed, in part, to document the developmental risk factors for exposed and not-infected children to support their inclusion in tracking and intervention services in their communities.

Multiple developmental risk with infection and with exposure. Children born to HIV positive women are at multiple developmental risk from both biological factors and aspects of their caregiving environment. For example, many HIV exposed infants are also

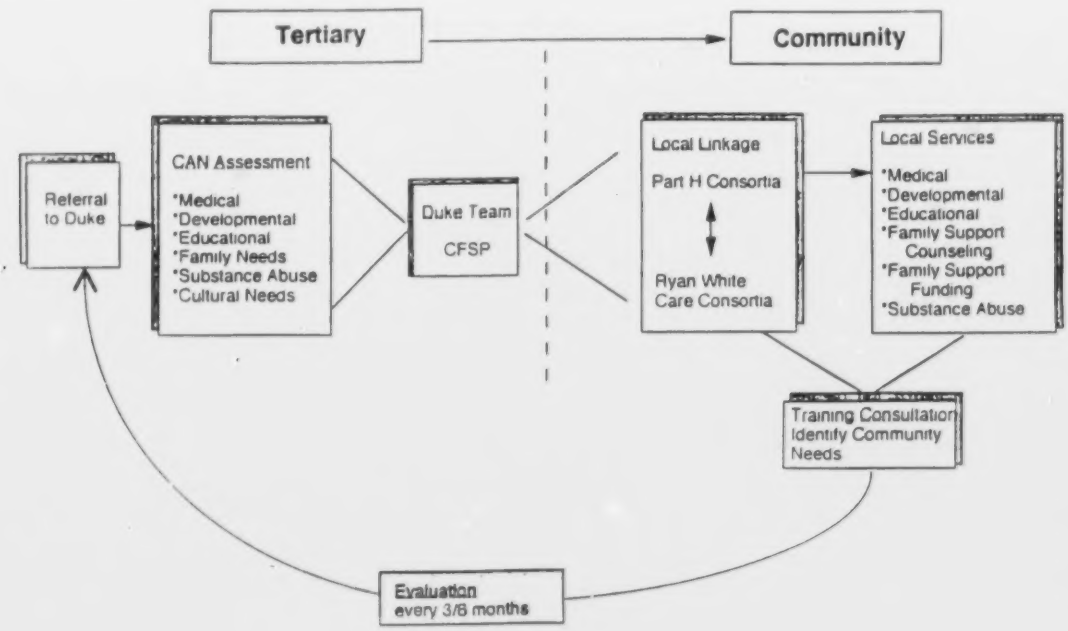
alcohol and/or drug exposed in utero. Multiple risk models suggest a multiplicative, not additive, effect on child behavior and development. Tracking and intervention approaches must address not only the direct effects of HIV on the infected infant but also myriad family and contextual factors contributing to the child's developmental risk and special needs. Project RISK assesses and addresses the multiple risk of a group of children who can be lost to services after their initial referrals to tertiary care hospitals and subsequent discharge with an HIV- diagnosis.

Family issues, including substance abuse. The lives of families with HIV infection are complex, with many broader cultural and individual challenges to the well-being of the developing child. Poverty is nearly ubiquitous in families living with HIV disease in a member or members. Even nearly 20 years after AIDS was first identified and nearly 6 years from the initial funding of Project RISK, families must deal with the stigma and shame associated with the disease—including, their first inclination to keep it secret with health providers, schools, and friends. Children often deal with the death of parent or parents; many will change homes and caregivers at least once during their childhood. Families with HIV present a broad range of service delivery needs, including substance abuse treatment for caregivers in many cases. These multiple contextual risks apply to the exposed not infected child as well as to the child with HIV disease. They are the primary focus of Project RISK.

Child needs in the community. A summary of the range of needs of a child with HIV exposure due to maternal infection suggests that community cased service delivery strategies must be developed to serve these children and their families if the child's potential is to be realized. Community resources must provide the basis for

comprehensive services of linked family and child care; yet there are a number of barriers to the family's access to community services. First, newborns are referred to tertiary care hospitals for diagnosis; too often, when the diagnosis is negative, the family returns to a life of secrecy in the community. The child is not identified for tracking and services. Second, adult and child providers are rarely as linked at the community level as they think they are. There is work to be done to link the family to the community in an acceptable way and to link services within a community toward the well being of the family as a whole. An intervention model must fit both the tertiary care setting and procedures and the functioning of the birth to 3 service system in the community. The Project RISK approach to address these conceptual issues, as originally proposed, can be found in Figure 1.

Figure 1. Project RISK model for linkage of tertiary to community care



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IV. DESCRIPTION OF THE MODEL AND PARTICIPANTS

The Project RISK model was implemented at the primary site (Duke University Medical Center, Durham NC) and at two replication sites (Baptist Hospital, Winston Salem NC; East Carolina University Medical Center, Greenville NC). The participants at each site included hospital Infectious Diseases clinic staff, primarily the social workers and physicians and the families who agreed to participate in the demonstration project, and the children and families who consented to the model demonstration. The characteristics of the families who participated are described in Tables 2 and 3; the children and families reviewed for the pilot project are described in Table 1.

Pilot study, chart review at Duke University Medical Center. At the request of the grant reviewers, the medical records of 50 consecutive admissions to the Duke clinic prior to the implementation of Project RISK were reviewed. The goal of the pilot study was to identify risk assessments and referral patterns in the tertiary care setting prior to the model demonstration. The children and families from the review are described in Table 1.

Table 1. Sample characteristics of the chart review pre-RISK

	Percent of n=50	
Child gender		
Male	48%	
Female	51%	
Child race		
African American	86%	
Bi-racial	8%	
White	6%	
HIV diagnosis		
HIV-infected	14%	7 of 50
Exposed/Not infected	86%	
Caregiving context by 12 months of age		
Biological parents	74%	
Extended family	14%	
Adoptive family	2%	
Foster care	10%	
Number of children in home	2.4	average

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The sample of 50 children used for chart reviews is instructive about the demographics of children who are HIV exposed and some sources of their multiple developmental risks and needs for developmental tracking, early intervention, and other child and family services. For example, over a quarter of the children are not living with their biological parents, and 12% are not in the custody of their biological parents. Eighty-six percent or 43 of the 50 children reviewed were found to be not HIV-infected; these are the children at most risk to be lost to tracking and community services without a transition plan as modeled in Project RISK. In the Evaluation section of this report, the community services utilized by this cohort of children and families are reported in Table 4. The findings from the chart review were prepared as a journal article, being revised for publication, and available here in the appended materials.

Participants at the primary site, Duke University Medical Center. Table 2 presents a description of the original model demonstration participants at Duke. For this initial implementation of the model, an assessment of family needs and child developmental status was conducted over several clinic visits. The assessment was completed before the child's first birthday and prior to discharge. There were 5 sections for each assesssment: current community services used, emotional well-being of parent, family needs survey, social support and the team's view of family needs. A cross disciplinary assessment tool was developed (see Care Providers' View of Family Community Needs and CFSP form, appended). This tool, combined with the family's view of their needs, presented a well-rounded picture of the family's current service delivery needs. The results of the needs assessment are presented in the Evaluation section of this final report.

Table 2. Descriptions of Project RISK participants at the Duke implementation site

	% of n=43
DOB of children = 4/24/94 to 2/20/95	
Race	
African American	93%
White	6%
Child gender	
Male	
Female	
Living Arrangements of child	
Biological parents	86%
Extended family	6%
Foster care	6%
HIV Diagnoses	
HIV-infected	10%
Exposed, not infected	90%

Participants at the replication sites. Table 3 describes the demographic features of the participants from the replication sites. A total of 35 children and their caregivers (all women) were recruited and followed by the replication sites. The majority (77%) of the children were African American, and only one child in this demonstration group was determined to by HIV-infected. These data reflect the changing epidemiology of Pediatric HIV that results from the intervention of antiretroviral therapies for pregnant women that are successful in preventing transmission. Accordingly, these data emphasize the concern for multiple risk HIV exposed and not infected children.

A comparison of tables 1, 2, and 3 emphasizes the similarity in samples of children exposed in utero to maternal HIV. Although child gender is generally equally distributed, there is a consistent predominance (>75%) of minority children represented. Ten to 20% of these children are living with caregivers who are not their biological parents, hence the stress of parental loss of their custody and being moved between caregivers during the ages critical to forming secure attachments. By and large, the mothers are single and poor. Only half of the primary caregivers are employed.

It is also interesting to note the variability between sites on certain items. For example, 62% of the mothers from Baptist Hospital in Winston Salem were employed at the time of interview; but only 31% of the mothers from ECU were employed. This difference may be due to the fact that Winston-Salem is a more urban setting with more employment opportunities whereas Greenville is very rural. Surprisingly, relatively little alcohol or drug use was reported by caregivers.

V. METHODOLOGICAL OR LOGISTICAL DIFFICULTIES AND CHANGES

In Phases 1 and 2, challenges to implementation varied by site. These barriers to implementation are informative about the problems that may or may not occur in outreach efforts, so each site is discussed separately.

Duke University (primary site). The first project change occurred at the request of the Department of Education reviewers, who requested that Project RISK staff conduct a retrospective chart review of HIV-exposed children attending our clinic. This was an involved and lengthy task requiring the time of the project coordinator, but well worth the effort given the "pilot" data derived.

The second, and more influential, implementation challenge related to concerns raised by (existing) clinic social workers. They were concerned that families would be confused if Project RISK personnel and clinic social workers were both providing direct services and family assessments. In response to these issues, linkages with community services were facilitated by clinic social workers rather than Project RISK personnel. In other words, the project, as designed, had Project RISK personnel providing the child and family assessments. The clinic social work staff did not want to do these assessments.

Table 3. Description of replication participants

	Entire Sample N=35 N (%)	Baptist N=16 N (%)	Carolinas N=6 N (%)	ECU N=13 N (%)
I. Children				
Gender				
Female	19 (54)	7 (44)	5 (83)	8 (62)
Male	16 (46)	9 (56)	1 (17)	5 (38)
Race				
African-American	27 (77)	11 (69)	4 (66)	12 (92)
Bi-racial	3 (8)	2 (12)	1 (17)	0
White	5 (14)	3 (19)	1 (17)	1 (8)
HIV status				
Seroreverter	26 (74)	9 (56)	6 (100)	11 (84)
Indeterminate	8 (22)	7 (44)	0	1 (8)
Infected	1 (36)	0	0	1 (8)
Born preterm (<37 wks)	7 (20)	2 (12)	3 (50)	2 (15)
In foster care by 12 mos.	7 (20)	2 (12)	1 (17)	4 (31)
II. Mothers/Caregivers				
Mean age (yrs)	27.9 (16-52)	28.2 (16-37)	31.5 (20-52)	24.1 (20-27)
Education				
< High school	13 (37)	8 (50)	2 (33)	3 (23)
High school/GED	11 (31)	3 (19)	2 (33)	6 (46)
> High school	11 (31)	5 (31)	2 (33)	4 (31)
Marital Status				
Single	26 (74)	10 (62)	4 (66)	12 (92)
Married	19 (26)	6 (38)	2 (33)	1 (8)
Employment				
Working	20 (57)	10 (62)	2 (33)	4 (31)
Not Working	15 (43)	6 (38)	4 (66)	9 (69)
Current substance use				
Using tobacco	15 (48)	7 (44)	4 (66)	4/9 (44)
Using alcohol	5 (16)	1 (6)	1 (17)	3/9 (33)
Using cocaine	0	0	0	0
Using marijuana	4 (13)	2 (12)	1 (17)	1/9 (11)
Using heroin	0	0	0	0
History of past use (sw report of alcohol and drug use)	8 (26)	4 (25)	2 (33)	2/9 (22)
III. Fathers				
Baby's father HIV +	9 (26)	6 (37)	2 (33)	1 (8)
Unknown	7 (20)	0	1 (17)	6 (46)
Baby's father living at home	12 (34)	8 (50)	2 (33)	2 (15)

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They claimed that the assessments would be too time consuming. On the other hand, they seemed threatened that another social worker (RISK project coordinator) would be interacting with "their" families. Fortunately, there was no competition regarding child assessments, since Dr. O'Donnell is the clinic psychologist as well as the project director; she performed all child assessments. We learned that, in most settings, the service delivery model needed to be implemented by clinic staff, not by outside providers.

A final implementation challenge was that several months prior to RISK (during the grant review phase) a nearby university began recruiting from the Duke Pediatric Infectious Diseases Clinic for a large-scale study. This study also involved in-clinic interviews creating, at times, scheduling conflicts with Project RISK, indicating that a the RISK model must be integrated into service delivery at the clinic level versus being seen as a "study" or "special project" as it was during the initial implementation. Happily, with the subsequent success of Project RISK at Duke and in replication (and with changes in the team social work staff), the primary site now integrates the model and is effective in its transition of exposed and not-infected children to community services, primarily the state's Child Services Coordinator system.

NC Baptist Hospital (replication site in Winston-Salem, NC). All aspects of Project RISK were successfully implemented at Baptist Hospital. The key to this success was that the clinic social worker (Dara Garner-Edwards) and the team lead physician, Dr. Charles Woods implemented all aspects of RISK except the developmental assessments. Garner-Edwards was able to facilitate community linkages based upon her existing relationship with the families. There was no role confusion between RISK staff and clinic staff, and subsequent to funding, the community agency charged with high risk follow up

are providing the developmental assessments and transition to community services at this site. NC Baptist Hospital demonstrated that the Project RISK model can be(and how it can be) very successful. The NC Baptist site provides the impetus for outreach activities in NC and surrounding states.

East Carolina University (replication site in Greenville, NC). The implementation of Project RISK at the ECU site was hampered initially, and outside of our awareness, by a less than strong commitment of the clinic physician. Upon much subsequent reflection and discussion with Dr. Jean Kinney, we concluded that, as we made our primary contact with the team social worker, the physician was not adequately included in planning. Hence, she was supportive in general but not completely engaged as was the clinic physician at NC Baptist. Given the commitment and interest in care for her patients, we concluded that this was a problem in implementation on our part; clearly, given a chance, this physician would have been on board and willing to monitor the quality of activities at that site. As a result of these problems, though, only one person was committed to the project, and she often did not follow through with RISK replication criteria. Then, this primary collaborator, the team social worker, left her position. Her replacement was helpful in collecting the 12 month data on children and families, but the model was never implemented fully at this site and does not continue at present. It can be said, however, that the project heightened the team's awareness of the multiple risk and needs of children and families who are discharged when diagnosed HIV-. This site will be open to outreach activities.

Carolinas Medical Center (replication site). The social worker from Carolinas Medical Center (Catherine O'Grady) expressed interest in participating in Project RISK.

Information about the developmental and family needs of six other children was obtained. However, shortly after all data were gathered O'Grady took another position within the Department of Pediatrics; and her position was left vacant. The site was never seen as a model replication site; again, the team here would most likely be open to outreach activities to find their own model for addressing the needs of their HIV- "graduates".

The major change in the community linkage component was the introduction of the community provider into the clinic at NC Baptist, thereby improving the transition model. This may represent the best model; or, we may find that each site must develop its own best model given the specifics and the personalities of hospital and community agencies.

The model design changes in the community education component involved responding to the formative evaluation data that: 1) education activities must occur at a local level and directly engage providers and 2) that so-called "adult" and "child" service providers, those who might address a child and family with HIV/AIDS, have much less communication than we (or they) would have estimated. Therefore, the RISK design was changed to 1) provide a community provider survey to verify these findings and 2) to re-organize the education activities as child and adult service providers' meetings in each community. As an outcome, the contacts made in these meetings were probably much more valuable than the educational agenda provided.

VI. EVALUATION FINDINGS

Component 1. Direct service and assessment. The service delivery needs of the children and families participating in RISK were assessed during the project implementation. These data provided the basis for transition to community service

providers for individual families in the project and also provides data to support the assumption that this group of children are characterized by their multiple high risk factors and service delivery needs. The assessments of referral utilization and needs across the sites (including the Duke chart review) were accomplished using Telfair's service delivery assessment tool and are reported in Table 4. The data reflect the referral's status by project end at that site. In other words, by project end, 13 or 81% of the children at Baptist Hospital were receiving Child Services Coordination; another needed the service, but contact with or agreement with the family had not been achieved yet.

It is worth noting the multiple needs and risk evident in the Telfair assessment data. Over 75% of the children were referred to community services by the Child Services Coordination mechanism used in North Carolina. Of these, a smaller number (<10%) were actually noted to be receiving early intervention. Some children were in the referral process for early intervention, and others are being tracked by the CSC system regarding their needs for early intervention. As noted earlier, a high number of children, 10 to 30% across sites, are in foster care; and approximately one-third of the children have been referred to Child Protective Services. One-tenth to nearly one-half, depending on site, of the families were referred for mental health services. The array of services for the poor is nearly ubiquitous in their use with this sample of children and families. Further child risk is documented with over 10% of the children having a primary caregiver who is on probation or parole, although there is variability across sites.

Table 4. Telfair community referral list by site

	Duke (charts)	Duke	Baptist	Carolinas	ECU
	N=50	N=43	N=16	N=7	N=13
	N (%)	N (%)	N (%)	N (%)	N (%)
Child Services					
Child Service Coordination					
Already receiving	15 (36)	21 (49)	13 (81)	6 (86)	1 (8)
Need service		2 (5)	1 (6)		2 (15)
Referred to service				1 (14)	
Early Childhood Intervention					
Already receiving	7 (14)	1 (2)	1 (6)		1 (8)
Need service		1 (2)			
Referred to service			1 (6)		
Dev. Evaluation Center					
Already receiving		3 (7)			
Need service		2 (5)			
Referred to service					
Foster Care					
Already receiving		10 (23)	2 (12)	1 (14)	4 (31)
Need service					
Referred to service					
Actually used service					
Respite Care					
Already receiving					1 (8)
Need service		4 (9)	1 (6)	4 (57)	
Referred to service					
PT/OT					
Already receiving		4 (9)	1 (6)		
Need service					
Referred to service					
Child Protective Services					
Already receiving	15 (30)	13 (28)			
Need service					
Referred to service				1 (14)	
HIV/AIDS Services					
Case management					
Already receiving		2 (5)	11 (69)	4 (57)	10 (77)
Need service				1 (14)	
Referred to service					
Actually used service					

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Table 4. Telfair community referral list, continued

	Duke (charts)	Duke	Baptist	Carolinas	ECU
	N=50	N=43	N=16	N=7	N=13
	N (%)	N (%)	N (%)	N (%)	N (%)
HIV Cons. /ASA					
Already receiving	8 (16)	2 (5)	11 (69)	2 (28)	3 (23)
Need service		1 (2)		2 (28)	
Referred to service			3 (18)		
HIV Support Groups					
Already receiving	4 (8)	3 (7)		2 (28)	
Need service		3 (7)			
Referred to service			4 (24)		
Volunteer Services					
Already receiving			2 (12)	2 (28)	
Need service				1 (14)	
Referred to service					
Health care/Counseling					
Public Health Clinic					
Already receiving	35 (70)	17 (40)	10 (62)	5 (71)	
Need service					
Referred to service					
Public Health Nursing					
Already receiving	15 (30)	3 (7)	1 (6)	1 (14)	
Need service					
Referred to service					
Home Health Nursing					
Already receiving	6 (12)	15 (28)	1 (6)	2 (28)	
Need service					
Referred to service					
Nutrition Services					
Already receiving		1 (2)	1 (6)		3 (23)
Need service					
Referred to service					
Local Doctor					
Already receiving	50 (100)	43 (100)	14 (87)	7 (100)	9 (69)
Need service					1 (8)
Referred to service					
Substance Abuse Treatment					
Already receiving	6 (12)	5 (12)	1 (6)		
Need service		8 (19)			
Referred to service					
Mental Health (Adult)					
Already receiving	10(20)		2 (12)	3 (43)	2 (16)
Need service				1 (14)	
Referred to service			1 (6)		
Mental Health (Child)					
Already receiving					
Need service					
Referred to service					

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Table 4. Telfair community referral list, continued

	Duke (charts)	Duke	Baptist	Carolinas	ECU
	N=50	N=43	N=16	N=7	N=13
	N (%)	N (%)	N (%)	N (%)	N (%)
Mental Health (Family)					
Already receiving					
Need service				1 (14)	1 (8)
Referred to service					
Food/Financial Services					
Church					
Already receiving		4 (9)	7 (44)	3 (43)	4 (31)
Need service					
Referred to service			1 (6)		
WIC					
Already receiving	40 (80)	38 (88)	16 (100)	7 (100)	12 (92)
Need service					
Referred to service					
Food Stamps					
Already receiving	31 (50)	25 (58)	10 (62)	4 (57)	9 (69)
Need service					1 (8)
Referred to service					
Shelter/Meals Program					
Already receiving		3 (7)	1 (6)		
Need service					1 (8)
Referred to service					
Disability/SSI					
Already receiving	21 (42)		5 (31)	1 (14)	1 (8)
Need service					
Referred to service				1 (14)	
AFDC					
Already receiving	33 (60)	7 (16)	8 (50)	3 (43)	3 (23)
Need service					
Referred to service					
Medicaid					
Already receiving	50 (100)	39 (91)	16 (100)	7 (100)	13 (100)
Need service					
Referred to service					
Co. Emergency Fin. Assis.					
Already receiving			1 (6)	1 (14)	
Need service					
Referred to service				1 (14)	
VA Benefits					
Already receiving			1 (6)		1 (8)
Need service					
Referred to service					
Transportation Services					
Already receiving	22 (44)	13 (30)	5 (31)	7 (100)	5 (38)
Need service					
Referred to service					

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Table 4. Telfair community referral list, continued

	Duke (charts)	Duke	Baptist	Carolinas	ECU
	N=50	N=43	N=16	N=7	N=13
	N (%)	N (%)	N (%)	N (%)	N (%)
Public Housing/Section 8					
Already receiving	10 (20)	8 (19)	7 (44)	4 (57)	
Need service					1 (8)
Referred to service					
Household Furnishings					
Already receiving		1 (2)		1 (14)	1 (8)
Need service		1 (2)		1 (14)	1 (8)
Referred to service					
Legal Aid					
Already receiving	3 (6)	1 (2)	1 (6)		
Need service					1 (8)
Referred to service			3 (18)		
Probation/Parole					
Already receiving	6 (12)	12 (28)		1 (14)	
Need service			1 (6)		
Referred to service					

Table 5 documents child risk related to the status of maternal HIV/AIDS. There was wide variability in mothers' health as indicated by the wide range of CD4 lymphocyte counts (10-975; <200 is seen as severely immune deficient). However, the majority of the sample of HIV-infected mothers (68%) rated their health as good or excellent. One mother at the NC Baptist site was too ill to complete the interviews, and she died this summer, 1999. Sixty percent of HIV-infected mothers reported acquiring their disease from unprotected sex. This reflects a national trend of increased heterosexual acquisition among women in the South. Of particular interest is the finding that very few women (8%) have made legal custody arrangements for their children. In North Carolina, parents have the option of securing stand-by guardianship. However, the process is cumbersome and requires that parents provide medical confirmation of their life threatening illness. Mothers, especially those who are not experiencing acute HIV symptoms, may not see the need for custody arrangements.

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Table 5. Maternal HIV Information

	Entire Sample N=35 Mean (range)	Baptist N=16 Mean (range)	Carolinas N=6 Mean (range)	ECU N=13 Mean (range)
Most recent CD4 count	506 (10-975)	468 (10-740)	434 (114-975)	615 (280-970)
HIV Symp. Total at 1st Interview	31.3 (20-66)	36.9 (33-66)	33 (23-48)	24 (20-27)
	N (%)	N (%)	N (%)	N (%)
Mothers with good/excellent health	24 (68)	12 (75)	6 (100)	6/8 (75)
Route of infection				
Unprotected sex	21 (60)	11 (69)	5 (83)	5 (38)
Drug use	2 (6)	2 (12)		
Unprotected sex w/user	3 (8)	2 (12)		1 (8)
Transfusion				
Needlestick	1 (3)	1 (6)		
Unknown	8 (23)		1 (17)	7 (54)
Legal custody arrangements for dependent children	3 (8)	3 (18)	0	0
Was AZT taken during pregnancy?				
Yes	29 (82)	15 (94)	6 (100)	8 (61)
Unknown	6 (17)	1 (6)	0	5 (38)
Initiated during what trimester?				
First trimester	12 (34)	5 (31)	2 (33)	5 (38)
Second trimester	14 (40)	8 (50)	3 (50)	3 (23)
Third trimester	3 (8)	2 (12)	1 (16)	0
Unknown	6 (17)	1 (6)	0	5 (38)
	Mean (range)	Mean (range)	Mean (range)	Mean (range)
How compliant was mother? (1= not at all; 5=completely)	3.9 (1-5)	4.0 (2-5)	3.3 (1-4)	4.4 (3-5)

As an indicator of mental health needs, Table 6 reports maternal psychological symptoms as reported by mothers on the Brief Symptom Inventory (BSI) at their first interview. According to the scoring manual of the BSI, an individual is considered to be in need of mental health intervention if their score is 62 or above on any scale. More than 30% the entire sample received a score of 62 or higher on the Psychoticism, Depression,

Obesessive-Compulsive, and Paranoid Ideation subscales. The Global Severity Index scale, the measure of overall distress, indicates that 17 to 31% of the mothers were impaired. These findings indicate a population with relatively high psychological distress. The data emphasize that a child-only focus for needs assessment will not adequately address the needs for services for the family, indeed, for the child's care giving environment.

Table 6. Maternal Psychological Symptomatology (Brief Symptom Inventory-First Interview)

	Entire Sample	Baptist	Carolinas	ECU
	N=29	N=16	N=6	N=7
	Time 1 Mean	Time 1 Mean	Time 1 Mean	Time 1 Mean
BSI Subscales				
Psychoticism	**59.9**	**57.6**	**59.2**	**63.0**
N (%) > 62	13 (45)	7 (44)	2 (33)	4 (57)
Somatization	**51.4**	**55.4**	**50.0**	**48.9**
N (%) > 62	6 (21)	5 (31)	1 (17)	0
Depression	**54.7**	**56.2**	**53.2**	**54.6**
N (%) > 62	9 (31)	5 (31)	2 (33)	2 (29)
Hostility	**56.3**	**58.6**	**55.8**	**54.4**
N (%) > 62	11 (38)	6 (38)	3 (50)	2 (29)
Phobic Anxiety	**51.1**	**52.1**	**48.8**	**52.4**
N (%) > 62	4 (14)	2 (12)	1 (17)	1 (14)
Obsessive-Compl.	**55.3**	**59.7**	**55.2**	**51.0**
N (%) > 62	13 (45)	9 (56)	3 (50)	1 (14)
Anxiety	**51.4**	**54.9**	**53.5**	**45.7**
N (%) > 62	6 (21)	4 (25)	2 (33)	0
Paranoid Ideation	**61**	**62.4**	**58.5**	**62.1**
N (%) > 62	17 (59)	10 (62)	3 (50)	4 (57)
Inter. Sensitivity	**54.2**	**56.9**	**52.3**	**53.3**
N (%) > 62	7 (24)	5 (31)	1 (17)	1 (14)
Global Sev. Index	**56**	**59.0**	**55.3**	**53.7**
N (%) > 62	8 (28)	5 (31)	1 (17)	2 (29)

In addition, given our learning about risk factors during the project implementation, the replication social workers were asked to determine whether the biological mothers of RISK participants had any of the risk factors found in Table 7, needs that were not measured directly in the original project design. Of interest, 29% of the

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entire sample had a history of substance use; and 23% had a history of domestic violence. Three of the 35 women included in these data were mentally retarded.

Child status and needs were primarily documented by developmental assessments at 6 and 12 months of age. The data report in Table 8 are derived from the Bayley Scales of Infant Development (2nd edition; 1993), using the Mental and Motor Scales. The average scaled score is 100, with a standard deviation of 15. The average score minus 1 standard deviation (85) is indicative of possible developmental delays in that area; a minus 2 standard deviation score of 70 marks developmental delay in that area. With reference to Table 8, the relative risk for developmental problems in this group of children is evident, particularly delays in the motor area. Approximately one-fourth of the children seen at Duke demonstrated some (1 standard deviation delays) by one year. At 12 months, the replication sample had 10 children with motor delays; 3 of these were significant.

Table 7. Social Worker Reported Maternal Risk Factors

	Entire Sample N=35 N (%)	Baptist N=16 N (%)	Carolinas N=6 N (%)	ECU N=13 N (%)
Risk Factor				
Mental retardation	3 (8)	2 (12)	0	1 (8)
Depression	7 (20)	4 (25)	2 (33)	1 (8)
Thought-disordered	1 (3)	0	1 (17)	0
Hx. of substance abuse	10 (29)	6 (37)	2 (33)	2 (15)
Hx. of domestic violence	8 (23)	5 (31)	2 (33)	1 (8)
Current domestic violence	2 (6)	0	2 (33)	0
Other risk factors				
Mom raised in fostercare	1 (3)			1 (8)
Teenage mom		1 (6)		

Table 8. Child developmental data at the 12 month (hospital discharge) assessment

	Duke site, 12 mo.	Replication sites, 6 mo.	Replication sites, 12 mo.
Mental Scale (mean; SD; range)	93.8(9.7) 76-109	96.7(11.6) 73-120	100.3 (12.3) 73-120
Motor Scale (mean; SD)	94.7(11.9) 74-120	84.1(17.6) 68-122	95.5(17.5) 52-124
% Mental score <85	n=5 (29%)	n=4(16%)	n=3(10%)
% Motor score < 85	n=4 (25%)	n=15(60%)	n=10(40%)
% Mental score < 70	n=0	n=0	n=1 (3%)
% Motor score < 70	n=0	n=5(20%)	n=3(10%)

Community linkages. The primary goal of this component was to facilitate a linkage 1) between child, family, and community agencies before discharge from the hospital clinic and 2) between services provided at the tertiary care hospital and the community. It was apparent through the original chart review that children were making transition back to their home communities without a service plan; only 15 of 50 (36%) children in the "pilot" survey of medical records had been referred to Child Services Coordination. Over the 6 years since the implementation of Project RISK a trend of improved community referral has emerged. At the end of the demonstration of the project at the Phase 1 Duke site, 49% were referred; subsequent to the end of the demonstration at Duke, the process continued to improve, and 100% are referred if parents agree. Approximately 90% of parents/caregivers agree, although there is still concern about the stigma of the disease and about disclosure in the community. At the end of the best replication site, 81% of the families had accepted referrals to Child Services Coordination and to community service delivery. A further demonstration of the effectiveness of the model replication at NC Baptist is that no children were referred to Child Protective Services.

The need for intra-community linkage became evident early in the implementation of Project RISK-- with the awareness that few child providers referred to adult providers and vice versa. This situation is particularly unacceptable in families with HIV in that there are imperative "adult" (e.g., HIV case managers, substance abuse treatment specialists) providers involved and critical "child" providers (e.g., CSC, early intervention). The need to address this service delivery gap for families provided the impetus for a major perturbation of component #3, education for community service providers.

To support the observation of this service delivery gap for families, service providers from 15 counties across North Carolina were interviewed in the Spring of 1996. Counties were chosen based on the residency of families with infants being cared for at the Duke Pediatric Infectious Diseases Clinic. Our goal was to interview providers who would represent a broad spectrum of traditional child and adult services. Specifically, initial contact letters and follow-up phone calls were made to at least three professionals within each of the identified counties, including

a) Child service coordination (CSC)- 14 interviewed
b) Early intervention services (ECI)- 9 interviewed
c) Women s substance abuse services (SAS)- 12 interviewed
d) Other (Ryan White or HIV Consortia staff)- 7 interviewed

CSC and ECI represent child providers, and substance abuse coordinators for women's services and HIV consortia or service agency representatives are categorized as adult providers. A total of 42 community providers participated in the interview. The duration of the interviews was approximately 60 minutes.

Most child and adult providers interviewed had extensive employment experience in the human services field. Child providers were employed in their county of residence for an average of 9 years and adult providers were employed in their county for an average of 6 years. The majority of adult providers had a Masters degree (70%) compared with 24% of child providers. Many of the providers had come into contact with and treated children and families affected by HIV/AIDS. Thirty percent of the Child Service Coordinators had at least one HIV-infected child in their caseload, and two-thirds of the adult providers had at least one HIV-infected adult. Furthermore, 57% of the child providers had a least one HIV-exposed child in their caseload.

Table 9 represents the array of services to which referrals were made for the local children and families affected by HIV/AIDS. Referral patterns for child providers are compared with those referrals made by adult providers. Of interest among the child services, CSC referred children to developmental services (e.g., physical therapy, speech therapy) substantially more often (86%) when compared to referrals made to developmental services by adult providers (50%). Although 50% of the adult providers referred to developmental services, no adult providers made referrals to child service coordination, a service in which nurses and social workers make home visits and complete developmental screenings for children at-risk for developmental problems. Most child service providers, however, had made referrals to adult substance abuse services (68%). Referrals to day care centers were made on a more regular basis by child providers (79%) than by adult providers (30%).

Although there are statewide HIV Care Consortia established as part of the Ryan White C.A.R.E. Act, the consortia was not known to the majority of child providers

(84%) and 40% of the adult providers. It is important to note, however, that the majority of the care consortia are not direct service providers; rather, they are administrative agencies designed to coordinate services for individuals infected by HIV/AIDS. Less than 50% of child providers and 60% of adult providers ever made referrals to HIV support groups.

Referral patterns to medical services show that, overall, child providers made more referral to home-based care (63%) and public health nursing (50%) in comparison to referrals ever made by adult providers (20% and 30%, respectively). Both providers made frequent referrals to community health clinics, although the majority of providers noted that their clients were already seeking health care from their local clinics.

Table 9. Referral pattern by provider, Spring, 1996 telephone survey

Services Referred	Child Providers		Adult Providers	
	N	%	N	%
Child -Related Services				
Child Service Coordination	14/14	100%	0/10	0%
Developmental Services	12/14	86%	5/10	50%
Day Care	15/19	79%	3/10	30%
Dep. of Social Services	17/19	90%	9/10	90%
Child Protective Services	14/19	74%	7/10	70%
HIV Related Services				
HIV Care Consortia	0/19	0%	2/10	20%
HIV Support Groups	8/19	42 %	6/10	60%
Medical Services				
Community Clinics	12/19	50%	3/10	30%
Public Health Nursing	9/18	50%	3/10	30%
Home Health Care	12/19	63%	2/10	20%
Mental Health Services	16/19	84%	9/10	90%
Substance Abuse Services	13/19	68%	NA	
Financial Services				
Medicaid	14/19	73%	6/10	60%
AFDC	13/19	68%	5/10	50%
SSI	18/19	95%	5/10	50%
Food Stamps	13/19	68%	4/10	40%
WIC	14/19	73%	4/10	40%
Transportation	18/19	95%	6/10	60%
Housing	16/19	84%	8/10	80%
Legal Services	13/19	68%	5/10	50%

Referrals to financial support services showed that, overall, child providers made more referrals than adult providers, particularly SSI, food stamps, and WIC services. As with referral to local community clinics, many providers noted that the majority of their clients were already receiving financial entitlement support benefits.

Referrals to support services such as transportation were made more frequently by child (95%) in comparison to those made by adult providers (60%). This may be because parents with children are more likely to require alternative forms of transportation. Child providers also appear to refer more frequently to legal services (68%) than those made by adult providers (50%). These rates are surprisingly low given the importance of planning prospectively for the child's health care and custody.

Table 10 represents how knowledgeable child and adult providers were of other providers in their community. Respondents were asked to give the full name and telephone number of several providers representing an array of services in their community. The following data represent the percentage of providers who were able to provide names and numbers of specific providers. As expected, child providers were able to identify other child service coordinators (93%) and early childhood interventionists (89%), where as adult providers had difficulty providing such information for child professionals (58% and 42%, respectively). Likewise child providers had difficulty identifying substance abuse professionals in their community (only 61%). Few child and adult providers were able to give identifying information for this resource (13% and 8%, respectively). More adult providers than child providers identified child protection workers (67% and 33%, respectively) than AFDC workers (22% and 17%, respectively),

although virtually all providers gave the telephone number for the Department of Social Services.

Table 10. Knowledge of Community Providers

Services Referred	Child Providers		Adult Providers	
	N	%	N	%
Child –Related Services				
Child Service Coordination	8/9	89%	5/12	42%
Developmental Services	13/14	93%	7/12	58%
Child Protective Services	16/23	70%	6/12	50%
HIV Related Services				
HIV Care Consortia	3/23	13%	1/12	8%
HIV Support Groups	6/22	27 %	5/10	50%
Medical Services				
Public Health Nursing	15/22	68%	2/10	20%
Home Health Care	17/22	77%	0/10	0%
Child Mental Health Services	14/20	84%	9/10	90%
Adult Mental Health Services	4/21	19%	9/10	90%
Substance Abuse Coordinator for Women 's Services	9/23	39%	NA	
Financial Services				
AFDC	5/23	22%	2/12	17%

No adult providers were able to provide both a name and a telephone number for home health care; and only 20% were able to provide such information for public health nurses. Child providers, on the other hand, were more knowledgeable about medical providers representing a broad array of services: home health (77%), public health nursing (68%), and community health clinics (70%). Both child and adult professionals were able to identify mental health professionals specializing with children (90%), whereas only 19% of child providers were knowledgeable about mental health professionals working with adults.

In the of Spring, 1997, Project RISK staff developed an interview for service providers who had participated in the community meetings during Phase 1. The first part of this telephone interview duplicated the questions asked during the 1996 interview.

Although the respondents were different in 1996 and 1997, the data provide some evaluation of the linkage component as addressed by the community meetings.

Table 11 represents the array of services to which referrals from one agency to another were made, as reported in 1997, for local children and families affected by HIV/AIDS. For the purposes of comparison with the earlier survey, referral patterns for child providers are compared with those referrals made by adult providers. Although the sample size was relatively small, there were some notable differences in the services accessed by the child and the adult service providers; and there are positive changes in referral patterns that may have been affected by the RISK community meetings.

In the 1997 survey, child service providers make more referrals to the organizations included in the interview than did adult service providers, with the highest referrals to the department of social services (75%) and public health/community clinic (88%). Substance abuse treatment organizations were the only category in which more referrals were made by adult providers (56%) than by child providers (50%). Adult service providers made the least referrals to public health nursing (11%) and child mental health services (11%). The largest discrepancies in referral patterns between child and adult providers occurred in developmental services, day care, AIDS service organization, public health/community clinic, and public health nursing, to which child providers made at least 40% more referrals than adult providers. Adult and child providers made comparable referrals to organizations offering financial support.

Table 11. Referral patterns by type of provider, Spring, 1997

Services Referred	Child	Adult	Child and Adult
Child-Related Services			
Child Service Coordination	2/8 (25%)	2/9 (22%)	0 (0%)
Developmental Services	5/8 (63%)	2/9 (22%)	0 (0%)
Day Care	5/8 (63%)	2/9 (22%)	1/5 (20%)
Department of Social Services	6/8 (75%)	5/9 (56%)	0 (0%)
Child Protection Services	4/8 (50%)	2/9 (22%)	0 (0%)
HIV/AIDS Services			
HIV Consortium	4/8 (50%)	4/9 (44%)	1/5 (20%)
HIV Support Groups	5/8 (63%)	5/9 (56%)	2/5 (40%)
AIDS Service Organization (ASO)	5/8 (63%)	2/9 (22%)	1/5 (25%)
Health Care/Counseling Services			
Public Health/Community Clinic	7/8 (88%)	4/9 (44%)	1/5 (20%)
Public Health Nursing	4/8 (50%)	1/9 (11%)	0 (0%)
Home Health	4/8 (50%)	2/9 (22%)	0 (0%)
Child Mental Health Services	3/8 (38%)	1/9 (11%)	0 (0%)
Adult Mental Health Services	5/8 (63%)	5/9 (56%)	0 (0%)
Substance Abuse Treatment	4/8 (50%)	5/9 (56%)	0 (0%)
Financial Support			
WIC	5/8 (63%)	3/9 (33%)	0 (0%)
Food Stamps	5/8 (63%)	3/9 (33%)	1/5 (20%)
SSI/Disability	5/8 (63%)	4/9 (44%)	1/5 (20%)
AFDC	4/8 (50%)	3/9 (33%)	1/5 (20%)
Medicaid	5/8 (63%)	5/9 (56%)	2/5 (40%)
Transportation	5/8 (63%)	5/9 (56%)	1/5 (20%)
Housing	5/8 (63%)	5/9 (56%)	1/5 (20%)
Legal Aid/Legal Services	4/8 (50%)	4/9 (44%)	0 (0%)

In the Spring 1996 interview, it was found that the statewide HIV Consortium was not known to the majority of child and adult providers. In fact, referrals to the HIV/AIDS service groups was not common. This was not the case in the March 1997 interview, where referrals to all HIV services included in the interview was 50% or greater for child providers, and the HIV Consortium was referred to by 50% of child providers and 44% of adult providers. This is seen as a major marker of success for the community education agenda of Project RISK. The AIDS service organization was referred to by 63% of the child providers, compared to only 22% of adult providers. From the 1996 to the 1997 interview, awareness of HIV organizations in the counties sampled has dramatically

increased. However, it is important to note that 2 out of the 9 total adult providers in the 1997 survey were not involved in making referrals; and, therefore, that portion of the interview was not applicable to them. Their lack of referral information most likely had an influence on the overall results of the survey and also on the comparison between adult and child providers. (The director of home health agency in Durham stated that she was not involved in making referrals, and a substance abuse counselor said that when she did get an HIV positive client, she made no referrals; she simply "called clinic A at Wake County mental health".)

Table 12 represents how knowledgeable the 1997 surveyed child and adult providers were of other providers in their community. Respondents were asked to identify several providers representing an array of services in their community. The following data show the percentage of providers who were able to provide the information requested, including specific name and telephone number to use to make a (meaningful) referral.

Table 12. Knowledge of other providers in the community, Spring, 1997

Person/Agency	Child	Adult	Child and Adult
Early Childhood Intervention (ECI)	3/8 (38%)	1/9 (11%)	0 (0%)
Child Service Coordination	3/8 (38%)	2/9 (22%)	0 (0%)
HIV Support Groups	1/8 (13%)	5/9 (56%)	3/5 (60%)
HIV Consortium	3/8 (38%)	4/9 (44%)	2/5 (40%)
Women's Coordinator for Substance Abuse	3/8 (38%)	3/9 (33%)	1/5 (20%)
AFDC	4/8 (50%)	4/9 (44%)	2/5 (40%)
Protective Services	5/8 (63%)	4/9 (44%)	1/5 (20%)
Public Health Nursing	4/8 (50%)	4/9 (44%)	1/5 (20%)
Home Health	4/8 (50%)	4/9 (44%)	0 (0%)
Adult Mental Health	5/8 (63%)	5/9 (56%)	2/5 (40%)
Child Mental Health	5/8 (63%)	2/9 (22%)	0 (0%)
AIDS Service Organization (ASO)	5/8 (63%)	1/9 (11%)	1/5 (20%)

As expected, child providers had considerably more frequent contact with early childhood intervention (38%), child service coordination (38%), and child mental health

(63%) than did their adult counterparts. While the adult providers had much more frequent contact (56%) with HIV support groups than did the child providers (13%), child providers had much more frequent contact with the AIDS service organization (63%) in comparison to adult providers (22%). Overall, a majority of providers interviewed were aware of other service providers in their community, with no major differences, other than those previously mentioned, between child and adult providers. Child service coordination and women's coordinator for substance abuse were the least frequently contacted, as a whole, by both child and adult providers, indicating a major need for community education in these areas.

Community education regarding HIV/AIDS. The primary Project RISK intervention toward heightened community provider education regarding pediatric HIV/AIDS and the needs of families with HIV/AIDS was the community networking meetings held in several counties. Most meetings included only one county, but two meetings included 2 or 3 smaller counties that work together and cross-refer clients to services. The community meetings were evaluated in two ways.

Follow up telephone interviews were conducted with providers who attended the first two community meetings held during Phase I. A total of 21 community providers, from Durham, Vance/Granville, and Wake counties, were interviewed throughout the month of March, 1997 (see Table 13). Interview participants were randomly chosen from a pool of meeting participants. Equal numbers of child and adult providers were selected to be interviewed (see Table 14). Follow up interviews were conducted an average of 6 months after the meetings. Providers who failed to respond to three phone calls were not

pursued. Interviews were provided by a single qualified interviewer who was familiar with the community meetings. The duration of the interview was approximately 10 minutes.

Table 13. County of community providers in evaluation interview sample

County	N
Durham	10/21 (48%)
Vance/Granville	6/21 (28%)
Wake	5/21 (24%)

Table 14. Community providers in evaluation interview sample

Category of Service Providers	N
Adult	9/21 (43%)
Child	8/21 (38%)
Adult & Child	5/21 (19%)

The first portion of the interview focused on referral and interagency knowledge (see above) to be compared with the Spring, 1996 survey (see above). The last portion of the interview concentrated on the community meeting itself, and how helpful it was for the providers who attended. Participants were asked to rate the helpfulness of the meeting on a scale of 1 to 5 (1 = not at all helpful, 5 = very helpful). General satisfaction with the meeting was expressed.

Approximately 66% of the interview participants gave the meetings a score of 4 in the question about meeting other service providers in the community. The providers who answered with less than a 3 did so because they were already well aware of other service providers in the community. Nevertheless, these providers asserted that overall the meeting was informative and helpful for those who did need to make connections in the community. Several providers mentioned that since the meeting they had been in contact with another community service provider whom they had met at the meeting. In fact, 6 providers--29% of those interviewed--had begun making referrals to HIV/AIDS services after the meeting or were making more referrals to HIV/AIDS services than they were

before. The data demonstrate the benefit of the community meeting in raising community awareness of these HIV services to the providers.

Approximately 53% gave the meetings a score of 4 in facilitating referrals. The providers who responded with less than a 3 did so because either they were not directly involved in referrals themselves, or because they were already well enough aware of all the community providers to whom they could refer.

Many participants offered their opinions of the community meeting and had very positive reactions to it. They felt it "met people's needs", was "very informative", and the "information presented was excellent". One provider felt that these meetings were "great" and should be held more than once a year. Another felt that the meeting "was extremely successful and necessary, specifically for those who needed direction". Several providers said that the community meeting was a good way to network and meet people. For one it "helped tremendously with linkages to pediatric services". Another commented that she was surprised to meet people at the luncheon whom she did not know and now feels that she "knows more people" to whom she can refer, "especially with her HIV clients".

After receiving feedback following the first community meeting, Project RISK staff included community agency participation in all stages of the meeting: from developing the invitation list to presenting at the meeting. To this end, RISK staff work very closely with local Ryan White HIV Consortia and Child Service Coordinators (Part H service providers). Both of these lead agencies now make formal presentations subsequent meetings explaining what services their agencies can provide and the nature of their umbrella services.

Subsequent community meetings were evaluation by a paper and pencil form for feedback. Essentially the feedback was the same as above, often with suggestions for 1) future meetings and 2) other agencies that could be included. The conclusion from the evaluations of the meetings is that they could be held in each community at regular intervals to address the integration of services for families in which adults and children have special needs.

VII. PROJECT IMPACT

Dissemination activities. The Project RISK model of integrated child and adult services was presented at each of the community meetings held throughout North Carolina. In addition, Drs. O'Donnell and Woods (lead physician at Baptist Hospitals) are planning to describe the model in the North Carolina Pediatric Association Newsletter later this year and possibly present at the annual meetings of the North Carolina Pediatric Association. The Project RISK model was also presented at OSEP's Early Childhood Projects' Annual Meeting in February, 1998. Other approaches to the dissemination of the findings related to child multiple risks and to the model for transition are being explored, especially in relationship to primary health care providers in North Carolina.

Publications. To date two articles have been prepared for publication. The first article discusses the findings from the Duke chart review (see appended materials) and their implications for the early childhood intervention practitioner. This paper was submitted to an early childhood journal and is undergoing revisions. The second article is still in progress and focuses on the community meeting as a means to develop integrated care for the HIV-exposed child and family. The community meetings article will be

submitted to a community-oriented journal such as Journal of Community Practice.

Planned journal articles include:

Topic	Journal Type
Multiple needs of the HIV-affected child and their family	Pediatrics
Early intervention with the HIV-affected child	Special education
Conducting research in the clinical setting	Social work

Implications for the field. The RISK model and its evaluation is instructive to the tertiary care centers that diagnose HIV-affected children as well as community providers who follow children once they no longer need the services of the hospital. RISK emphasizes the need for beginning the transition from the tertiary care center to the community almost immediately upon entering the tertiary care setting. Indeed, the ideal situation is for families to view the transition from tertiary care to the community as one seamless continuum of care.

The RISK model may be relevant to other child conditions for which specialty care is sought and re-integration into community care desirable. The gap between tertiary care hospitals and community services is never in the best interest of the child and family; and transition is often difficult. In addition, RISK demonstrated (unplanned) a gap between adult and child service providers in the community. This gap in community services is impressive in the agencies' denial of it---however, the intervention of community meetings and problem solving around multiple risk, multiple needs families was successful in pointing out and, to some extent, closing the gap. This finding is relevant to conditions other than HIV/AIDS; indeed, it is relevant to the care of medical conditions or

environmental risks that affect the children and adults in a family, e.g., substance abuse, other chronic illnesses.

VIII. FUTURE ACTIVITIES

The goal of Project RISK was for the model to be implemented into standards of clinical care. This is occurring at the primary site (Duke) and at Baptist Hospitals without requiring additional funding. We are considering the feasibility of submitting an outreach grant to the U.S. Department of Education or to the American Academy of Pediatrics.

Other future activities involve the dissemination of the data on the multiple needs of the HIV-exposed child and family to primary care providers in the community. If a link to community services is not made from the tertiary care hospital, the most likely contact with be with primary health care in the community. If the pediatrician, for example, is aware of the multiple factors affecting this child and the increased incidence of developmental and behavioral difficulties for the developing child, he/she can insure appropriate follow-up as a part of routine health care. Indeed, this is the optimal model for community care that is integrative of health and early intervention providers.

IX. ASSURANCES

The full and final report has been sent to ERIC and copies of the title page and abstract/executive summary have been sent to the other addresses as requested.

NOTE: The Project RISK staff, our collaborators in hospitals and communities, and the participating children express our gratitude to the U.S. Department of Education, Office of Special Education and Rehabilitation for the opportunity to examine this increasingly important area of caring for children whose quality of life is threatened by biological risks and by aspects of their caregiving context.

Appended Material

- Multidisciplinary Assessment
- Community Passport
- Chart Review Article
- Wake County Provider Directory
- Meeting Roster from Surry County
- Slides from Community Meetings
- Duke Informed Consent
- Evaluation for Community Meetings
- Care Providers' View of Family Community Needs
- Community Service Family Plan

Multidisciplinary Assessment Package

Initial Demographic and Caregiving RISK Information

Child's name _____

Child's ID# _____

Date of interview _____

Person interviewed_____

SECTION A: SOCIODEMOGRAPHICS AND FAMILY STRUCTURE

Race of baby _____

1= African American
2= White
3= Native American
4= Hispanic
5= Bi-racial
6= Other _____

Caregiver's date of Birth? ____/ ____/ ____
month day year

What is caregiver's marital status? _____

1= Never Married
2= Married
3= Married- Common Law
4= Separated
5= Divorced
6= Widowed
7= Engaged

How long has caregiver lived at her current address?

____ Weeks ____
____ Months ____
____ Years ____

How far did caregiver go in school? ____ ____

1= Less than high school
2= GED
3= High school diploma only
4= More than high school- Vocational training
5= More than high school- College

Caregiver's Definition of Family

Please tell me the first name of the members of your family, starting with yourself and the baby.

Name	Gender	Age How old is	What is ____'s relationship to the baby?	What is ____'s relationship to you?	Does ____ currently live in the house ? 1=no 2=yes	What kinds of things does ____ do for you?	What kinds of things does ____ do for the baby)?	How close is _____ to the baby? 1=not at all close 3=somewhat close 5=very close

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ease tell me the names of other people in your house:

(Other Persons in Household)

Name	Gender	Age How old is	What is ____'s relationship to the baby?	What is ____'s relationship to you?	Does ____ currently live in the house? 1=no 2=yes	What kinds of things does ____ do for you?	What kinds of things does ____ do for the baby)?	How close is _____ to the baby? 1=not at all close 3=somewhat close 5=very close

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Who would you say is the head of your household?

_____

Now I'm going to ask you some questions about your work history.

Has caregiver ever worked? ____

1= No If no, skip to # __
2= Yes

Does caregiver currently have a job (PAID EMPLOYMENT)?

1= No **If no, skip to # __**
2= Yes
If yes,
A. What do you do? _____

Where does the baby usually stay while the caregiver is at work?

(Check all that apply)

A. ____ Child Home Alone
B. ____ With Family
C. ____ Daycare Program
D. ____ Babysitter
E. ____ Exchange with others
1. What do you exchange?
_____
F. ____ Community Center
G. ____ Other;
1. Specify _____

Think back over the past year and tell me how much difficulty you had with paying your bills.

Would you say you had: ____
4= A great deal of difficulty
3= Quite a bit of difficulty
2= A little difficulty
1= No difficulty at all

Maternal Social Support Index

Now I'm going to ask you about the who helps you with child care and household chores.

Item I

a. Who fixes the meals _____

b. Who does the grocery shopping? Anyone else? _____

c. Who disciplines the children? _____

d. Who fixes things around the house? _____

e. Who does the inside cleaning? _____

f. Who works outside around the house? _____

g. Who pays the bills? _____

h. Who takes care of car problems? _____

i. Who takes the children to the doctor when they are sick? _____

j. Who puts the baby to bed? _____

k. Who feeds the baby first thing in the morning? _____

Item II

a. How many relatives do you see once a week or more? _____

b. Is this:

_____ 1) often enough
_____ 2) too often
_____ 3) not often enough
_____ 4) mixed, depends on relatives

Item III

a. How many people can you count on in times of need? _____

Item IV

a. How many people in your neighborhood do you think would be able to help you in taking care of your children for a couple of hours if needed? _____

Item V

a. How happy are you in the way your mate lets you know that he feels or thinks?

_____ 1) happy
_____ 2) not happy
_____ 3) not sure

Item VI

a. Are there persons over 14, not including your partner, either inside or outside the home, with whom you have regular talks?

_____ 1) yes
_____ 2) no

b. Which of these people do you talk to the most? _____

c. How happy are you with your talks with this person?

_____ 1) happy
_____ 2) not happy
_____ 3) not sure

Item VII

a. Do you belong to any social, religious, educational, or political organizations?

_____ 1) yes
_____ 2) no

b. If yes, how often do you attend meetings for each organization?

_____ 1) once a month or less
_____ 2) more than once a month

c. For church members: are you a member of any committee or do you have other duties in your church?

_____ 1) yes
_____ 2) no

SECTION B: BABY'S FATHER

Is the baby's father alive? _____

1= No **If deceased, skip to # 31**
2= Yes

If yes,

A. Does he have any health problems? ___

1= No
2= Yes

If yes,

1. Specify : _____

Is the baby's father living at home?

1= No
2= Yes **If yes, skip to #___**

If no,

A. Where is he? ____

1= Somewhere in town
2= Moved out of town
3= In jail
4= In hospital
5= Whereabouts unknown
6= Other;
1. Specify _____

SECTION C: CAREGIVER'S HEALTH (infected only)

When was caregiver diagnosed with HIV? _____

What is the most recent T4 count? _____

Risk factor for HIV exposure _____

1= Drug use
2= Unprotected sex with drug user
3= Unprotected sex
4= Transfusion

Use of AZT during pregnancy

Was AZT taken during pregnancy? _____

1= No
2= Yes **If no, skip to #___**

If yes, then in what trimester did mother begin taking it? _____

1= First trimester
2= Second trimester
3= Third trimester

For social worker only.

How compliant, in your estimation, was the baby's mother in taking her AZT?

Not at all compliant **Completely compliant**

1 2 3 4 5

HIV Symptom Checklist

I'm going to list symptoms sometimes associated with HIV infection. Please tell me if you've had a symptom in the previous month. (Show cue card and explain).

	I do not have it				**I suffer from it constantly**
Hearing loss	1	2	3	4	5
Night sweats	1	2	3	4	5
Rashes	1	2	3	4	5
Nasal Congestion	1	2	3	4	5
Vomiting	1	2	3	4	5
Swollen glands	1	2	3	4	5
Weight loss	1	2	3	4	5
Diarrhea	1	2	3	4	5
Headaches	1	2	3	4	5
Numbness	1	2	3	4	5
Sore throat	1	2	3	4	5
Muscle weakness	1	2	3	4	5
Hearburn	1	2	3	4	5
Non-productive cough	1	2	3	4	5
Vision problems	1	2	3	4	5
Shortness of breath	1	2	3	4	5
Fever	1	2	3	4	5
Difficulty swallowing	1	2	3	4	5
Chills	1	2	3	4	5
Female problems (yeast infections, etc.)	1	2	3	4	5

In the last 6 months, have your symptoms interfered with taking care of your baby ____

1= No
2= Yes
3= Sometimes

If yes or sometimes,
A. Explain: _____
_____

In the last 6 months, have your symptoms interfered with you getting along with your baby? ____

1= No
2= Yes
3= Sometimes

If yes or sometimes,
A. Explain: _____
_____
_____

How would you describe your physical health now? ____

1= Poor
2= Fair
3= Good
4= Excellent

How many packs of cigarettes per day do you smoke? ____

1= do not smoke
2= less than 1/2 pack/day (LOW)
3= 1/2 - 1 pack /day (MODERATE)
4= more than 1 pack /day (HIGH)

Over the past few months, about how many drinks have you had per day? ____

1= no alcohol consumed in past few months
2= 1-2 drinks/day OR less than one 6 pack of beer/weekend (LOW)
3= 3-7 drinks/day OR one 6 pack of beer/weekend(MODERATE)
4= 8 or more /day OR more than one 6 pack of beer/weekend (HIGH)

Stress confidentiality

Over the past few months how often have you used cocaine or crack? ____

1= no use
2= once a month or less (LOW)
3= 2-3 times/month (MODERATE)
4= 4 or more times /month (HIGH)

A. How did you use it? ____

1= Smoking
2= Snorting
3= Intravenous injection

Over the past few months how often have you used marijuana? ____

1= no use
2= once a month or less (LOW)
3= 2-3 times/month (MODERATE)
4= 4 or more times /month (HIGH)

Over the past few months how often have you used heroin? ____

1= no use
2= once a month or less (LOW)

3= 2-3 times/month (MODERATE)
4= 4 or more times /month (HIGH)

A. How did you use it? ____

1= Smoking
2= Snorting
3= Intravenous injection

Have you ever received substance abuse treatment? ____

1= No
2= Yes

If **no**, would you be interested in talking to someone about treatment?

_____
_____

Project RISK Family Needs Survey

Child's name _____

Child's ID# _____

Date of interview _____

Child's Date of birth _____

Person interviewed_____

Family Needs Survey

Now I'm going to read you a list of needs expressed by parents of special children. Let me know if you don't need help, you're not sure, or you do need help with each item.

	Do not need help with this	Not sure	Need help with this
Needs for Information			
1. I need more information about my child's condition.	1	2	3
2. I need more information about how to handle my child.	1	2	3
3. I need more information about how to teach or help my child.	1	2	3
4. I need more information on how to play with or talk with my child.	1	2	3
5. I need more information about the services that my child might need in the future.	1	2	3
6. I need more information on the services that are currently available for my child.	1	2	3
7. I need more information about how children develop and grow in general.	1	2	3
Needs for Support			
1. I need to have someone in my family that I can talk to more about problems.	1	2	3
2. I need to have more friends that I can talk to	1	2	3
3. I need to have more opportunities to meet and talk with parents and children like us.	1	2	3
4. I need to have more time just to talk with my child's doctors or nurses.	1	2	3
5. I would like to meet more regularly with a counselor, (psychologist, social worker, psychiatrist) to talk about problems.	1	2	3

2. I need more help in getting special equipment for my child's needs.	1	2	3
3. I need more help in paying for therapy, daycare, or other services that my child needs.	1	2	3
4. I or the baby's father needs more counseling or help in getting a job.	1	2	3
5. I need more help paying for babysitting or respite care.	1	2	3
6. I need more help paying for toys that my child needs.	1	2	3

Family Functioning

1. Our family needs help in discussing problems and reaching solutions.	1	2	3
2. Our family needs help in learning how to support each other during difficult times.	1	2	3
3. Our family needs help in deciding who will do household chores, child care, and other family tasks.	1	2	3
4. Our family needs help in deciding on and doing recreational activities. .	1	2	3
5. Our family would like to talk with other families with children in similar situations.	1	2	3

6. I need to talk more to a minister who could help me deal with problems.	1	2	3
7. I need reading material about other parents who have a child similar to mine.	1	2	3
8. I need to have more time for myself.	1	2	3
9. I need to know someone who can be with my child when I can't be.	1	2	3

Explaining to Others

1. I need more help in explaining my child's condition to either my parents or the baby's father's parents.	1	2	3
2. The baby's father needs help in understanding and accepting my child's condition.	1	2	3
3. I need more help in how to explain my child's condition to his/her brothers or sisters.	1	2	3
4. I need help in knowing how to respond when friend, neighbors, or strangers ask questions about my child's condition.	1	2	3
5. I need help explaining my child's condition to others.	1	2	3

Community Services

1. I need help locating a doctor who understand me and my child's needs.	1	2	3
2. I need help locating a dentist who will see me child.	1	2	3
3. I need helping locating baby sitters or respite care providers who are willing and able to care for my child.	1	2	3
4. I need help in locating a day care center or preschool for my child.	1	2	3
5. I need help in getting appropriate care for my child in our church or synagogue nursery during services.	1	2	3

Financial Needs

1. I need more help paying for expenses such as food, housing, medical care, clothing, or transportation.	1	2	3

Project RISK BSI

Child's name _____

Child's ID# _____

Date of interview _____

Child's Date of birth _____

Person interviewed_____

Now we're going to focus on you and how you have been feeling lately.
I am going to read a list of problems people sometimes have. Please listen to each one carefully, and tell me the number (SHOW CUE CARD AND DESCRIBE) that best describes HOW MUCH THAT YOU HAVE HAD THIS PROBLEM DURING THE PAST 7 DAYS INCLUDING TODAY. If you have any questions about any of the items that I read, please ask about them.

Let's do an example first:

How much have you had:

1. Bodyaches

0 Not at all
1 A little bit
2 Moderately
3 Extremely

IN THE LAST WEEK, HOW MUCH HAVE YOU HAD:

*1. Nervousness or shakiness inside ____

2. Faintness or dizziness ____

3. The idea that someone else can control your thoughts ____

4. The feeling that others are to blame for most of your troubles ____

*5. Trouble remembering things ____

6. Feelings of being easily annoyed or irritated ____

7. Pains in heart or chest ____

8. Feelings of being afraid in open spaces or on the streets ____

*9. Thoughts of ending your life ____

IN THE LAST WEEK, HOW MUCH HAVE YOU HAD...

10. Feelings that most people cannot be trusted ____

*11. A poor appetite or not felt hungry very often ____

12. Feelings of being suddenly scared for no reason ____

13. Temper outbursts that you could not control ____

*14. Feelings of being lonely even when you are with people ____

*15. Feelings like you can't get things done ____

*16. Feelings of loneliness ____

0 Not at all
1 A little bit
2 Moderately
3 Extremely

*17. Feelings of being blue ____

*18. Feelings of no interest in things ____

*19. Feelings of fearfulness ____

20. Problems with your feelings being easily hurt ____

IN THE LAST WEEK, HOW MUCH HAVE YOU HAD...

21. Feelings that people are unfriendly or dislike you ____

*22. Feelings that you are inferior to others or that others are better than you ____

23. Nausea or upset stomach ____

24. Feelings that you are watched or talked about by others ____

*25. Trouble falling asleep ____

26. To check and double check what you do ____

*27. Difficulty making decisions ____

28. Feelings of being afraid to travel on buses, subways, or trains ____

29. Trouble getting your breath ____

30. Hot or cold spells ____

31. To avoid certain things, places, or activities because they frighten you ____

*32. Trouble with your mind going blank ____

33. Numbness or tingling in parts of your body ____

34. The idea that you should be punished for your sins ____

*35. Feelings of hopelessness about the future ____

IN THE LAST WEEK, HOW MUCH HAVE YOU HAD...

*36. Trouble concentrating ____

37. Feelings of weakness in parts of your body ____

*38. Feelings of being tense or keyed up ____

0 Not at all
1 A little bit
2 Moderately
3 Extremely

*39. Thoughts of death or dying ____

40. Urges to beat, injure, or harm someone ____

41. Urges to break or smash things ____

42. Feelings of self-consciousness with others or thoughts that others are judging you ____

43. Feelings of being uneasy in crowds, such as shopping or at a movie ____

THE LAST WEEK, HOW MUCH HAVE YOU HAD

44. Feelings that you are not close to another person _____

45. Spells of terror or panic (cue if necessary) _____

46. Problems with getting into frequent arguments _____

*47. Feelings of nervousness when you are left alone _____

48. The belief that others do not give you proper credit for your achievements or don't notice when you do things well _____

0 Not at all
1 A little bit
2 Moderately
3 Extremely

*49. Feelings of being so restless that you couldn't sit still _____

*50. Feelings of worthlessness or being no good _____

51. The belief that people will take advantage of you if you let them _____

*52. Feelings of guilt _____

53. The idea that something is wrong with your mind _____

12 month Demographic and Caregiving RISK Information

Child's name _____

Child's ID# _____

Date of interview _____

Person interviewed_____

SECTION A: BABY'S HEALTH

Baby's HIV status _____

1= Seroreverter
2= Indeterminate
3= HIV-Infected

SECTION B: CAREGIVING TRANSITONS

Did the child have the same caregiver during the first year of life?? ____

1= No
2= Yes

If no, who is the new caregiver? _____

1= Family member
2= Foster parent
3= Other _____

Date of transition _____

Reason for transition?

_____

_____

_____

SECTION C: EMPLOYMENT

Does caregiver currently have a job (PAID EMPLOYMENT)?

1= No **If no, skip to # __**
2= Yes
If yes,
A. What do you do? _____

Where does the baby usually stay while the caregiver is at work?

(Check all that apply)

- **A. ____ Child Home Alone**
- **B. ____ With Family**
- **C. ____ Daycare Program**
- **D. ____ Babysitter**
- **E. ____ Exchange with others**
  - **1. What do you exchange?**

    _____
- **F. ____ Community Center**
- **G. ____ Other;**
  - **1. Specify _____**

Think back over the past several months and tell me how much difficulty you had with paying your bills.

Would you say you had: ____

4= A great deal of difficulty
3= Quite a bit of difficulty
2= A little difficulty
1= No difficulty at all

SECTION D: CAREGIVER'S HEALTH (infected only)

What is caregiver's most recent T4 count? _____

HIV Symptom Checklist

I'm going to list symptoms sometimes associated with HIV infection. Please tell me if you've had a symptom in the previous month. (Show cue card and explain).

	I do not have it				**I suffer from it constantly**
Hearing loss	1	2	3	4	5
Night sweats	1	2	3	4	5
Rashes	1	2	3	4	5
Nasal Congestion	1	2	3	4	5
Vomiting	1	2	3	4	5
Swollen glands	1	2	3	4	5
Weight loss	1	2	3	4	5
Diarrhea	1	2	3	4	5
Headaches	1	2	3	4	5
Numbness	1	2	3	4	5
Sore throat	1	2	3	4	5
Muscle weakness	1	2	3	4	5
Hearburn	1	2	3	4	5
Non-productive cough	1	2	3	4	5
Vision problems	1	2	3	4	5
Shortness of breath	1	2	3	4	5
Fever	1	2	3	4	5
Difficulty swallowing	1	2	3	4	5
Chills	1	2	3	4	5
Female problems (yeast infections, etc.)	1	2	3	4	5

In the last 6 months, have your symptoms interfered with taking care of your baby ____

1= No
2= Yes
3= Sometimes

If yes or sometimes,
A. Explain: _____
_____

In the last 6 months, have your symptoms interfered with you getting along with your baby? ____

1= No
2= Yes
3= Sometimes

If yes or sometimes,
A. Explain: _____
_____
_____

How would you describe your physical health now? ____

1= Poor
2= Fair
3= Good
4= Excellent

How many p[illegible]; of cigarettes per day do you smoke? ____

1= do not smoke
2= less than 1/2 pack/day (LOW)
3= 1/2 - 1 pack /day (MODERATE)
4= more than 1 pack /day (HIGH)

Over the past few months, about how many drinks have you had per day? ____

1= no alcohol consumed in past few months
2= 1-2 drinks/day OR less than one 6 pack of beer/weekend (LOW)
3= 3-7 drinks/day OR one 6 pack of beer/weekend(MODERATE)
4= 8 or more /day OR more than one 6 pack of beer/weekend (HIGH)

Over the past few months how often have you used cocaine or crack? ____

1= no use
2= once a month or less (LOW)
3= 2-3 times/month (MODERATE)
4= 4 or more times /month (HIGH)

A. How did you use it? ____

1= Smoking
2= Snorting
3= Intravenous injection

Over the past few months how often have you used marijuana? ____

1= no use
2= once a month or less (LOW)
3= 2-3 times/month (MODERATE)
4= 4 or more times /month (HIGH)

Over the past few months how often have you used heroin? ____

1= no use
2= once a month or less (LOW)
3= 2-3 times/month (MODERATE)
4= 4 or more times /month (HIGH)

A. How did you use it? ____

1= Smoking
2= Snorting
3= Intravenous injection

SECTION D: PERMANENCY PLANNING

If something happened to you, who would you want to have custody of your baby?

_____

A. Why? _____

B. Do you think _____would get custody of (TARGET)? ____

1= No
2= Yes
If no,
1. Why not?

_____

_____

If yes,
2. Explain

_____

Does _____know you would like him/her to have custody of the baby? ____

1= No
2= Yes
If no,
1. Why not?

_____

_____

If something happened to you, do you think that the baby will be able to live with his/her brothers and sisters? ____

1= No
2= Yes
3= Some but not others

If no or some,
A. Why not?

_____

_____

_____

Have you made legal arrangements for the custody
of the baby should something happen to you?____

1= No
2= Yes

Do you have a will? ____

1= No
2= Yes

Child's name _____

Child's ID# _____

Telfair Community Service List

To be completed in an ongoing basis. Record month/year for services needed, referred to and actually used.

Service Type	Already Receiving Service	Need Service		Referred to Service	Actually Used Service	Other Comments
Child services		CG	SW			
Child Service Coordination						
Early Childhood Intervention						
Developmental Evaluation Center						
Foster care/Adoption						
Respite Care						
PT/OT						
Speech/Hearing Evaluation						
HIV/AIDS Services						
Case management						
AIDS Service Agency						
HIV Consortium						
HIV Support Groups						
Volunteer Services						

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Service Type	Already Receiving Service	Need Service		Referred to Service	Actually Used Service	Other Comments
Health care / Counseling		CG	SW			
Public Health/ Community Clinic						
Public Health Nursing						
Home Health Care						
Nutrition Services (beyond WIC)						
Local Doctor						
Battered Women's Shelter						
Drug/Alcohol Rehabilitation						
Mental Health Services (Adult)						
Mental Health Services (Child)						
Mental Health Services (Family)						
Food/Financial & General Services						
Church						
WIC						
Food Stamps						
Shelter/Meals Program						
Disability / SSI/ Social Security						
AFDC						
Medicaid						

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Service Type	Already Receiving Service	Need Service		Referred to Service	Actually Used Service	Other Comments
County Emergency Financial Assistance						
VA Benefits						
Transportation Services						
Public Housing/Section 8						
Household Furnishings/Clothing						
Legal Aid						
Probation/Parole						

Sample Community Passport

Child's Name

City

County

Your Guide to Community Resources

Child Services

- Child Service Coordinator
- DEC
- Day Care
- DSS

Health Care/Counseling

- Local MD
- Health Department
- Hospice
- WIC
- Poison Control
- ER
- Mental Health
- Substance Abuse
- Shelter

General Services

- Transportation
- Housing Authority
- Legal Aid
- Medicaid

Miscellaneous

- Consortia
- Case Manger
- Suppport Group

Other Important Numbers

_____

_____

_____

_____

Chart Review Article

The Community Service Utilization of Families of Young Children Who are Exposed to Human Immunodeficiency Virus (HIV)

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In revision: do not quote without permission of authors.

The Community Service Utilization of Families of Young Children Who are Exposed to Human Immunodeficiency Virus (HIV)

Infants and young children with HIV/AIDS and those who are exposed prenatally to maternal HIV but not infected are an important group in need of community based early intervention services. Early interventionists are and will be working with a large group of children who are at developmental risk because of maternal HIV/AIDS and its associated factors and a smaller group of children who have the disease. To accommodate the needs of families of children who are HIV-infected and HIV-exposed, early intervention teams are being asked to facilitate new interagency and interdisciplinary referrals for families. There is presently limited information regarding the service utilization of families of children who are HIV-infected and even less information on services utilized by children who are HIV-exposed but not infected. In order to better understand the service configurations of such children, a retrospective chart review was undertaken. The current study examined the range of services utilized by 50 children and there families who attended the Pediatric Infectious Diseases Clinic at Duke University Medical Center (DUMC) for evaluation of HIV-exposure. Recommendations for future early intervention practice and policy are presented.

Background

Several aspects of the changing epidemiology of HIV/AIDS in the U.S. contribute to the early interventionists' involvement with this population of children and families: the distribution of the disease, increasing numbers of children who are HIV-exposed but not infected, and the changing locus of services for children and families.

Distribution of disease. The HIV/AIDS epidemic in the U.S. has undergone a dramatic demographic shift since the early 1980's. HIV is spreading more rapidly in women than any other group in the United States with greatest increases in the rural south (CDC, 1994). At the end of 1994, the cumulative total of women reported with AIDS

was over 58,000 (compared to 20,000 in 1992) (HIV/AIDS Surveillance Report, CDC, 1994). This estimate does not include women who are HIV-infected but have not yet become symptomatic enough to meet the CDC criteria for "AIDS". Nearly 85% of women with AIDS are of childbearing age and able to transmit the virus vertically (mother to fetus). Without intervention (see below) vertical transmission occurs in roughly 20-30% of pregnancies in the U.S.

This rise in infection rates among women is paralleled in children. Currently, over 85% of all cases of pediatric HIV/AIDS are due to vertical transmission (CDC, 1994). 1,017 cases of AIDS (not HIV infection) in children (<13) were reported in 1994, representing an 8% increase from 1993. However, since the determination in one study that prenatal, intrapartum, and postnatal drug treatment can reduce the vertical transmission rate from 25% to 8%(Conner, Sperling, Gelber, Kiselev, Scorr, O'Sullivan et al, 1994), the face of pediatric HIV/AIDS is shifting towards fewer children infected with HIV and a greater number of children exposed prenatally to and living in families with HIV/AIDS but who are not HIV-infected.

Children who are HIV-exposed but not infected. The child referred to here as exposed but not infected is exposed prenatally to maternal HIV infection but may or may not have acquired the Human Immundeficiency Virus (HIV-1). All children born to women who are HIV-infected are born with the mothers' antibodies to HIV-1. The child with antibodies to HIV is referred to as HIV seropositive; but, in the case of the newborn, it does not mean the child has acquired the virus. Indeed, the majority of children will shed these maternal antibodies and have no evidence of acquiring the virus. The child who, by 12-15 months, no longer has the antibodies to HIV is referred to as a seroreverter. He or she does not have HIV-1 infection and will not have the disease HIV/AIDS.

An understanding of the terms seropositive, seroreversion, and HIV infection are important for early interventionists to differentiate between a child who lives in the

environment of parental HIV versus the child who is also HIV-infected. The process of seroreversion can cause confusion among parents and other caregivers. A mother who is HIV-infected may mistakenly believe, that because her baby has seroreverted, she (the mother) also no longer carries the virus. Early interventionists can provide accurate information to caregivers as well as emphasize the importance of early medical care for a child whose HIV status has not yet been determined.

Children who are HIV-exposed but not infected are, nonetheless, often at risk for nonoptimal psychosocial and developmental outcomes. Diamond, Gurdin, Wiznia, Belman, Rubinstein, and Cohen (1990) compared the neurodevelopmental status of groups of children who were HIV infected with a group of children were exposed but not infected. Children who were HIV-infected were significantly more likely to have greater neurological and cognitive deficits. However, 5 of the 20 not infected children had significant neurological involvement; and 8 had cognitive delays. The Diamond group (1990) propose that this high incidence of developmental difficulties in children who are HIV negative is related to both biological and social factors including poverty, living in a drug seeking family environment, and (frequently) in utero drug exposure. In addition to developmental risk posed by factors associated with HIV exposure, these children must cope with a stigmatizing illness, eventual death of their mother and/or father, and changes of caregiver: events that can seriously interfere with emotional and social functioning (Siegel, Messagno, & Christ, 1990).

Locus of services. The shift in the demographics of HIV/AIDS, medical advances, and the unique psychosocial factors associated with HIV/AIDS can challenge existing service delivery systems, both those based in tertiary care centers and those in the community. Tertiary care centers continue to play a vital role in the diagnosis and treatment of children exposed to HIV/AIDS. As noted, the diagnosis of HIV infection in a newborn and young infant is complicated by the presence of maternal antibodies that result in the child testing positive for HIV on those tests that detect antibodies to HIV.

However, advances in the biomedical technology of testing for the virus itself now allow health professionals to determine the child's infection status with 90% validity by the age of 6 months (Borkowsky, Krasinski, Pollack, Hoover, & Ilmet-Moore, 1992). Most community health centers are not equipped to perform the lab tests necessary to do these tests for the virus; therefore, children must be followed initially in a tertiary care center.

Once children are identified as not HIV-infected, they will transition to community based care. The child with HIV infection continues to receive specialized health services at a tertiary care hospital. The tertiary care center can provide clinical trials of drugs not yet licensed for general use and other state of the art care not available locally. Both groups of children will require, as well, an array of health, developmental, and psychosocial services from their community.

Children with HIV/AIDS are living longer than in the earlier periods of this disease. With the use of early identification, anitretroviral treatments, and prophylactic medicines for opportunistic infections, the mean child age at death has increased from 2 to 3 years to 8 to 12 years (McKinney, R. data from the Duke Pediatric AIDS Clinical Trials Group). Historically, children infected with HIV spent much of their time in the hospital. Today these children are eligible for and need infant, preschool, and school services in their home communities. Communities now play a large role in the care of children and parents with HIV/AIDS.

In summary, the changes in the distribution of HIV/AIDS places increased numbers of young children at risk for acquiring the disease and/or living with parental HIV/AIDS. It is anticipated that, with prevention efforts for vertical transmission, there will be a larger number of children who are prenatally exposed to maternal HIV but not, themselves, infected with the virus and a smaller group who have HIV/AIDS. The case is made that both groups of children are eligible for Part H early intervention services by merit of an array of biological and social-economic risk factors. Finally, with the improved longevity of adults and children with HIV/AIDS, the child who is HIV-infected

will be long time consumers of special services in communities. The community based early interventionist is in the position to be a primary referral for the child and family and to facilitate the wide array of other services required by them. To assist early interventionists in understanding these family needs, the following questions have been addressed by this study.

Study Questions

1. What community services do children exposed to HIV and their families utilize?

This question provides information about what services families actually use. It has been suggested that children infected with HIV are best served by cross disciplinary teams that provide developmental services at an early age (Dokecki, Baumeister, & Kupstas, 1989). It would be difficult to argue against this model's approach, but it is not evident that communities have actually implemented this level of care.

2. Do patterns of service utilization vary based on the living arrangement of the child?

It is estimated that between 25 and 35 percent of infants with HIV/AIDS will not be cared for by their biological parents or extended family (Tourse & Gurðin, 1988). The service utilization patterns may be different based upon living arrangement. If so, it will be important to examine the pattern closely to determine if there are groups not adequately served.

3. Are there differences between services utilized by children who are HIV-exposed and are not infected and children who are HIV- infected ?

It is necessary to investigate service utilization differences based upon the HIV status of the child. An implicit assumption is that children who are HIV-infected require more services than children who are HIV-exposed; but, given the risk factors associated for family HIV/AIDS, the assumption may not be correct.

METHODS

Study Design

This report represents a descriptive study of existing community service referral patterns for children and families affected by HIV/AIDS. Referrals from the tertiary care hospital setting to community based services are summarized in terms of 1) agencies to which families were referred, 2) referral patterns as they varied by the living arrangement of the child, and 3) referral patterns as they varied by HIV infection status of the child. For the study the data on referrals made from the tertiary care center to community services were documented until the child was 18-24 months of age or time of discharge from the tertiary hospital's outpatient clinic.

Sample

Charts from 50 children seen in Duke University Medical Center's (DUMC's) Pediatric Infectious Diseases Clinic from 10/5/91 to 11/15/93 were reviewed. The sample was selected from consecutive admissions to the outpatient clinic and included only children seen for diagnosis of vertical transmission of HIV and seen first at less than 3 months of age. Data regarding referrals to community services were included until the children were 18-24 months of age or at the time those children determined to be seroreverters were discharged from the clinic. Documentation of referrals and services utilized were carried out by a social worker.

Descriptive data on the sample are found in Table 1. The majority of children were African American (86%), lived with biological parents (74%), and are HIV-exposed but not infected (86%). Since Duke has been the primary referral center for children with or at risk for HIV/AIDS in NC, these demographic data are generally representative of pediatric HIV in the state during the study period.

Insert Table 1 About Here

Description of Instrument

For the purposes of this study **use of resources** was defined as the caregiver's accessing and utilizing health care and related community resources that was available to them as documented in the chart. Measurement of use was based on the documentation of the type of referred service/program documented in the medical chart of the child and logged onto a modified version of the Parent Actual Social Support Resource Scale. The scale was originally developed to be administered to caregivers of children who were HIV-infected and exposed but not infected. For the purposes of this study, the instrument was modified such that service referral and utilization was determined by information in the chart rather than collected from the caregiver. The measure was based on a list of essential resources most often needed by HIV-infected caregivers developed in consensus meeting between the third author and providers in the Pediatric Infectious Diseases clinic. The scale groups resources into four services/program categories that include: a) child services (e.g., infant stimulation services); b) HIV/AIDS services (e.g., AIDS services agency); c) health care/counseling (e.g., health department); and d) financial support (e.g., AFDC, SSI). Services were scored as either "used" or "not used". Service use was mediated by the adequacy of referral made on the caregiver's behalf by the Pediatric Infectious Diseases clinic's staff.

RESULTS

1. What community services do children exposed to HIV and their families utilize?

Insert Table 2 About Here

Table 2 represents the array of services to which there were referrals for the entire sample, including children who were determined to be HIV-infected and those who were not. Of interest among the *Child Services, 34% of children received Child Service* Coordination, a program based in the Health Departments of North Carolina. Nurses and social workers make home visits and complete developmental screening with those children deemed at-risk for developmental problems for family or biological reasons; they make community service referrals as needed. All children followed by the Pediatric Infectious Disease Clinic at Duke are eligible for Child Service Coordination. Although over 1/3 of children received Child Service Coordination, only 14% actually received developmental services.

Utilization of services from the Department of Social Services (DSS) was described separately from Child Protection Services (CPS). Local DSS's often provided basic services such as transportation and assistance with housing on a voluntary basis, whereas utilizing CPS indicated allegations of abuse and/or neglect were made and involvement with the agency was mandatory.

Although there are statewide HIV care consortia established as a result of the Ryan White C.A.R.E. Act, *HIV/AIDS Services were not used by many families.*

Services utilized within the *Health Care/Counseling section are primarily health* care related. Seventy percent of families utilized services from the public health or community health clinic. According to their charts, 100% of all children had an identified

primary health care provider in their local community. Mental health and drug treatment services were utilized by a relatively small group of people (20% and 12%, respectively).

The utilization of *Financial Support* services reflects the low income of families in North Carolina with HIV/AIDS. One hundred percent of families received Medicaid, and 66% received AFDC. Many services utilized by children and their families are poverty related services.

2. *Do patterns of service utilization vary based on the living arrangement of the child?*

Insert Table 3 About Here

While children living with biological parents and extended family are more likely to receive Child Service Coordination (50% and 42%, respectively), children in foster/adoptive care are much more likely to receive developmental services (50% vs. 11%, $X^2 = 5.8$, $p < .05$, Fisher's Exact Test). There is a trend for children living with biological/extended family to receive tracking services and children in foster/adoptive families to receive actual developmental services. *HIV/AIDS Services* were only utilized by biological families.

Within *Health Care/Counseling*, biological (70%) and extended (100%) families used public health / community health clinics; but few used home health services(11%). Foster/ adoptive families were less likely to use public clinics (33%) than biological/ extended but more likely to utilize home health services(33%).

A striking pattern within Financial Support services is that when children are placed into foster care/adoption, they seem to move out of poverty. No children in foster/adoptive families received AFDC, although 100% received Medicaid. Children who

are placed in foster care are automatically eligible for Medicaid and eligibility is not based upon the income of the foster family.

3. Are there differences between services utilized by children who are HIV-exposed and not infected and children who are HIV- infected ?

Insert Table 4 About Here

The comparison between services utilized by children who are HIV-exposed (not infected) and children who are HIV-infected is characterized by more similarities than differences. Overall, the differences between the two groups appear to be related specifically to disease status. For example, within Child Services, there are few differences between groups with the exception of developmental services: only 9% of children exposed to but not infected received developmental services, whereas 43% of children infected with HIV received these services.

There is another disease related difference within *HIV/AIDS services*. Forty-three percent of children with HIV infection received services from the HIV Consortium, but only 12% of children with HIV exposure received services. Parents who are HIV-infected are eligible for services regardless of whether their child is HIV-infected.

There are relatively few differences between the two groups *within Health Care/Counseling* with the exception of home health. *Twenty-eight percent of children who are HIV-infected received home health compared with 9% of HIV-exposed. Again, this is likely to be related to the fact that a sick child is more likely to require home health than a healthy child.*

Financial Support maintains the same disease-specific pattern. That is, the primary difference in this section relates to receiving SSI/disability. Eighty-six percent of children with HIV infection received SSI/disability compared to only 35% of children who

are HIV-exposed. The families of children exposed to HIV but not infected received SSI/disability because of parental illness unless the child had a non HIV-related significant medical or developmental problem.

DISCUSSION

The results of this descriptive study were presented for overall findings, referral as related to the child's living arrangement, and referrals as related to the child's HIV infection status. First, it is evident from Table 2 that children and families living with HIV/AIDS need a wide array of services from community services, including health and mental health care, child developmental (Part H) services, financial support, as well as services specific to HIV/AIDS. Many services used by children and families are poverty related, reflecting the low socioeconomic status of most families living with HIV/AIDS in rural states like North Carolina. It may be that area of financial support should be a priority for family needs assessments by community based early interventionists.

It if difficult to understand why only 36% of children received Child Service Coordination and even fewer yet received developmental services. It is possible that at a tertiary care hospital, only those with developmental needs are referred to developmental tracking services while community providers may base decisions on eligibility.

Another puzzling finding is that very few families utilized services through the Ryan White HIV-Consortia. Theoretically, 100% of parents and children who are HIV-infected are eligible for these services. Funding limitations may play a role in this finding. For example, one consortia from a fairly urban area in NC had funding to maintain only 30 open cases.

In terms of the summary of services used by different child living arrangements, there is a clear trend toward increased utilization of developmental services and a movement out of poverty when a child, regardless of HIV status, is placed in foster care. Children in foster care appear to have greater access to a wider array of services than children living with biological/extended families. It is possible that foster/adoptive parents

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have other sources of referral and support based in the foster care/adoption agencies that placed the children. One challenge for early interventionists, then, is to improve the delivery of services for equal access regardless of the child's living arrangements.

The HIV status of the child does seem to relate to the number of services a child received; however, the differences between the HIV-infected and exposed but not infected groups are primarily disease specific. There is very little differences in the financial support area and some children who are exposed and not infected still require health/mental health and child services including DSS and developmental services. The financial area is particularly similar and early intervention personnel cannot assume the lack of eligibility of child and family needs for the child who is determined not to be infected.

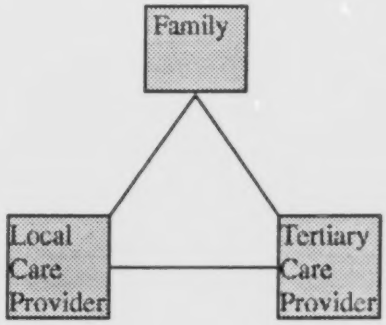
It is likely that early interventionists will come into contact with children who are both HIV-exposed and HIV-infected. These children are entitled to services under Part H of the Individuals with Disability Education Act (IDEA). Children who are perinatally HIV-exposed are typically referred to tertiary care centers for diagnosis of their HIV status. When children are determined not to be HIV-infected, they too often are discharged and returned to their communities as though HIV infection were the only challenge faced by these young children. It is necessary to move beyond a disease-bound model and consider the entire array of factors that place children exposed to HIV at risk for poor developmental outcomes: poverty, familial substance use, multiple placements, and ultimate loss of parent. Agencies involved in providing early intervention services must come to recognize the child who is HIV-exposed but not infected as a legitimate consumer of their services.

Another important practice consideration for early interventionists is that of confidentiality. The maintenance of confidentiality is critical to providing the best care for all families and children. However, the unique features associated with HIV/AIDS magnify the need for confidentiality. The following section highlights issues of confidentiality relevant to early interventionists.

Confidentiality: Special considerations for early interventionists

The special circumstances of an infectious disease such as HIV/AIDS warrants some comments for the early interventionist on the issue of confidentiality. Regardless of the child's disease status, extremely delicate and complex issues concerning confidentiality and disclosure mediate the relationship between families affected by HIV, their local service providers, and their tertiary care center. Care coordination across sites and ultimate service access and provision may easily become compromised by the restricted and irregular flow of information within the triangular relationship between families, local providers, and tertiary care providers (see Figure 1). Ease of flow of communication among members of this triangle is very helpful to the child's health care as well as assessing needs for auxiliary services in the tertiary hospital and community. Additionally, greater interagency coordination decreases the likelihood of inefficient service duplication and service gaps.

Fig. 1 Flow of information



BEST COPY AVAILABLE

Differences in the flow of information will occur depending on the degree of consent for HIV-related information and the flow between local and tertiary service providers granted by families or agencies that have legal custody of the child. Families and custodial agencies are in control of the flow of information to either care provider. It is the parent's legal right to disclose or withhold disclosure of the child or family disease status from any school or service delivery agency. The only exception to this right is if members of the child's health care team determine the child to be a public health risk. For example open lesions or frequent biting may result in the team informing the local public health director who, then, may disclose the diagnosis to a school or agency. Regardless of the interventionist's opinion about agencies' need to know, for him/her to provide that disclosure is patently illegal.

Understanding families reasons for restricting the flow of information can enhance the relationship between the interventionist and the families they serve. Despite the advantages of disclosure to agencies, families may have very legitimate reasons for restricting communications. Unfortunately, the stigma and history of discrimination against individuals and families with HIV disease is a realistic source of worry for an affected family. In a small town, overlap between professional service providers and a family's broader social network may translate a professional referral for service into a public disclosure of an individual's HIV status. Also, families confronting their own HIV infection and the potential HIV infection of their newborn child are under a huge psychological and existential burden. The insertion of multiple professionals with multiple agendas into their family system may undermine a family's sense of control, self-

determination, and dignity. Families need the opportunity to establish trusting relationships with agencies.

The triangular model presented above is a significant simplification. Each point on the triangle (family, local provider, tertiary care provider) is a set containing a number of possible members. The family may consist of a biological mother, grandparents, aunts, uncles, and other extended members in addition to the child or children. The pool of potential service providers at the local level may include physicians, nurses, social workers, child service coordinators, and early interventionists. A similar number of professionals are likely to operate within the tertiary care center. Identifying the legitimate lines of communication concerning a case within and across these systems can be a challenging undertaking. It is necessary to first consult with the parent or other caregiver regarding which family members as well as which agencies are aware of the child's/family's HIV status.

Conclusion

Several limitations of this study require noting. First, the chart review was retrospective. It is possible that children who are currently being referred to the Pediatric Infectious Diseases Clinic are utilizing a different constellation of services due to changes in service delivery systems. A current prospective project is examining family needs and service utilization patterns. Second, the data collected are only as reliable or valid as the individual recording the child's needs/services. Fortunately, the documentation provided by the team's social workers and primary care providers (usually nurse practitioners and physician's assistants) is thorough. Third, this information was collected from a chart and

not directly from the caretaker of the exposed child. It is possible that caretakers have a different view of service delivery needs than providers. The prospective study mentioned above is currently collecting information from families as well as health providers.

Despite these limitations, this study provides additional information to early interventionists about the range of needs of children and families with HIV/AIDS and the need to consider children who are HIV-exposed but not infected as children entitled to services. We encourage opening dialogues with colleagues who serve adults who are HIV-infected as another access point to families. The unique features associated with pediatric HIV exposure call for a rethinking of traditional roles and the generation of creative approaches to reaching this growing population of two groups of children: those who are living with HIV/AIDS and those who are affected by the disease with parents and/or other family members. Finally, maintaining confidentiality and respecting families' decisions regarding disclosure are extremely important when providing care to children and families living with HIV/AIDS. Early interventionists are in a position to provide care that considers the family in its entirety and to make the necessary community linkages.

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Table 1. Chart Review Demographic Information

Race:		
African American	43/50	(86%)
Bi-racial	4/50	(8%)
White	3/50	(6%)
Average # of children in home: 2.4		
Living Arrangements of child:		
Biological parents	37/50	(74%)
Extended family	7/50	(14%)
Adoptive family	1/50	(2%)
Fostercare	5/50	(10%)
Diagnoses		
HIV-infected	7/50	(14%)
Exposed/Not inf.	43/50	(86%)

Table 2. Services Utilized by Children Exposed to HIV

A. Child Services	Services Utilized
1. Child Service Coordination	18/50 (36%)
2. Developmental services (i.e., early intervention, PT/OT)	7/50 (14%)
3. Day care	11/50 (22%)
4. Department of Social Services	35/50 (70%)
5. Child Protection Service	15/50 (30%)
B. HIV/AIDS Services	
1. HIV Consortium	8/50 (16%)
2. HIV Support Groups	4/50 (8%)
C. Health Care/Counseling	
1. Public Health/Community clinic	35/50 (70%)
2. Public Health Nursing	15/50 (30%)
3. Home Health	6/50 (12%)
4. Local Primary Health Care	50/50 (100%)
5. Mental Health Services	10/50 (20%)
6. Drug Treatment	6/50 (12%)
D. Financial Support	
1. WIC	40/50 (80%)
2. Food stamps	31/50 (62%)
3. SSI/disability	21/50 (42%)
4. AFDC	33/50 (66%)
5. Medicaid	50/50 (100%)
6. Transportation	22/50 (44%)
7. Housing	10/50 (20%)
8. Legal aid/Legal Serv.	3/50 (6%)
9. Probation/parole	6/50 (12%)

Table 3. Services Utilized by Living Arrangements

	Biological Parents (n=37)	Extended Family (n=7)	Foster care/ Adoptive (n=6)
A. Child Services			
1. Child Service Coordination	14/37 (50%)	3/7 (42%)	1/6 (17%)
2. Developmental services (i.e., early intervention, PT/OT)	4/37 (11%)	0	3/6 (50%)
3. Day care	7/37 (19%)	2/7 (28%)	2/6 (33%)
4. Department of Social Services	27/37 (73%)	4/7(57%)	4/6 (66%)
5. Child Protection Service	10/37 (27%)	5/7 (71%)	0
B. HIV/AIDS Services			
1. HIV Consortium	8/37 (22%)	0	0
2. HIV Support Groups	4/37 (11%)	0	0
C. Health Care/Counseling			
1. Public Health/Comm. clinic	26/37 (70%)	7/7 (100%)	2/6 (33%)
2. Public Health Nursing	13/37 (35%)	2/7 (28%)	0
3. Home Health	4/37 (11%)	0	2/6 (33%)
4. Local Primary Health Care	37/37 (100%)	7/7 (100%)	6/6 (100%)
5. Mental Health Services	5/37 (13%)	3/7 (43%)	2/6 (33%)
6. Drug Treatment	4/37 (11%)	1/7 (14%)	0
D. Financial Support			
1. WIC	31/37 (84%)	4/7 (57%)	5/6 (83%)
2. Food stamps	26/37 (70%)	4/7 (57%)	1/6 (17%)
3. SSI/disability	18/37(49%)	3/7 (43%)	0
4. AFDC	29/37 (78%)	3/7 (43%)	0
5. Medicaid	37/37 (100%)	7/7 (100%)	6/6 (100%)
6. Transportation	22/37 (59%)	0	0
7. Housing	10/37 (27%)	0	0
8. Legal aid/Legal Serv.	1/37 (3%)	1/7 (14%)	1/6 (17%)
9. Probation/parole	5/50 (10%)	1/7 (14%)	0

Table 4. Services utilized by children who are HIV-exposed vs. children who are HIV- infected

	Children who are HIV-exposed (n=43)	Children who are HIV-infected (n=7)
A. Child Services		
1. Child Service Coordination	15/43 (35%)	3/7 (43%)
2. Developmental services (i.e., early intervention, PT/OT)	4/43 (9%)	3/7 (43%)
3. Day care	7/43 (16%)	4/7 (57%)
4. Department of Social Services	31/43 (72%)	4/7 (57%)
5. Child Protection Service	13/43 (30%)	2/7 (28%)
B. HIV/AIDS Services		
1. HIV Consortium	5/43 (12%)	3/7 (43%)
2. HIV Support Groups	4/43 (9%)	0
C. Health Care/Counseling		
1. Public Health/Comm. clinic	30/43 (70%)	5/7 (71%)
2. Public Health Nursing	13/43 (30%)	2/7 (28%)
3. Home Health	4/43 (9%)	2/7 (28%)
4. Local Primary Health Care	43/43 (100%)	7/7 (100%)
5. Mental Health Services	8/43 (19%)	2/7 (28%)
6. Drug Treatment	5/43 (12%)	0
D. Financial Support		
1. WIC	35/43 (81%)	5/7 (71%)
2. Food stamps	27/43 (63%)	4/7 (57%)
3. SSI/disability	15/43 (35%)	6/7 (86%)
4. AFDC	30/43 (70%)	3/7 (43%)
5. Medicaid	43/43 (100%)	7/7 (100%)
6. Transportation	19/43 (44%)	3/7 (43%)
7. Housing	8/43 (19%)	2/7 (28%)
8. Legal aid/Legal Serv.	3/43 (7%)	0
9. Probation/parole	6/43 (14%)	0

Wake County Provider Directory

DIRECTORY

Services for Individuals and Families Living with

HIV/AIDS

in Wake County

Project RISK

Duke University Medical Center

US Department of Education

#H024B30012

This is a directory of select services represented at the Wake County Community HIV/AIDS Luncheon conducted on May 3, 1996. Services are listed alphabetically by name of agency. We hope you find it helpful.

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education, #HO24B30012

Who to call when you don't know who to call

If you are unable to find a referral point in this directory or if you need general information about HIV, two sources of additional information are:

- Eastern NC HIV/AIDS Consortium
  P.O. Box 1434
  Greenville, NC 27834
  Phone: (919) 830-6165
  Fax: (919) 830-0277

The primary concern of the Eastern NC HIV/AIDS Consortium is to develop and ensure delivery of comprehensive health and support services to people living with HIV disease. They serve a nine county region which includes Wake County.

- National AIDS Hotline
  Phone: (800) 342-2437

The National AIDS Hotline can provide an additional source of information on HIV.

AIDS Care Branch

Contact: Shawn Aldridge
Title: Assistant Director
Address: P.O. Box 27687

Raleigh NC

Phone: (919) 715-3112 **Facsimile:** (919) 715-3144

E-mail:

County: Wake **Primary Client:**

SERVICES:

OTHER INFORMATION:

The mission of the AIDS Care Branch is to ensure the provision of a comprehensive continuum of health care and supportive services for individuals and families with HIV infection with a focus on home and community-based services.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Brothers to Brother

Contact: Delmonte Jefferson
Title: Project Coordinator
Address: Wake County Dept. of Health
P.O. Box 14049
Raleigh NC 27620

Phone: (919) 250-3990 **Facsimile:** (919) 250-3984

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Peer mentoring
Counseling

OTHER INFORMATION:

Provides peer mentoring and counseling on family life information to young males 9-14 years old. The goal is to develop positive decision-making skills in young men leading to the prevention of substance use, crime, and violence.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Community Partnerships, Inc.

Contact: Linda Lang
Title: Executive Director
Address: 3522 Haworth Drive

Raleigh NC 27609

Phone: (919) 781-3616 **Facsimile:** (919) 782-1485

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Early Intervention Services
Supported Employment
Family Services/Social Work
Consultation, Training, and Technical Assistance
Support Services and Coordination

OTHER INFORMATION:

Services are provided for children and adults with developmental disabilities or traumatic brain injury. This includes child early intervention, after-schoo/summer opportunities for youth, employment for adults, and assistance with general family needs.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Community Partnerships, Inc.

Contact: Kelli Rushing
Title: Early Intervention Services Manager
Address: 3522 Haworth Drive

Raleigh NC 27609

Phone: (919) 781-3616 **Facsimile:** (919) 782-1485

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Early Intervention Services
Supported Employment
Family Services/Social Work
Consultation, Training, and Technical Assistance
Support Services and Coordination

OTHER INFORMATION:

Services are provided for children and adults with developmental disabilities or traumatic brain injury. This includes child early intervention, after-schoo/summer opportunities for youth, employment for adults, and assistance with general family needs.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Eastern NC HIV/AIDS Consortium

Contact: Kimberly Scott
Title: Project Director
Address: P.O. Box 1434

Greenville NC 27834

Phone: (919) 830-6165 **Facsimile:** (919) 830-0277

E-mail:

County: Wake **Primary Client:** Adults

SERVICES:

Primary Medical and Dental Care
Outpatient SA and Mental Health Treatment
Medical Supplies & Hospice
Counseling, Transportation, Legal services
Nutrition Therapy and Emerg. Financial Asst.

OTHER INFORMATION:

A variety of services are offered. To use these services a person must be HIV positive and initial contact should be made to the HIV Coordinator in Wake County. Services include Medical and Dental Care, Medical Supplies, and emergency financial asst.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Project Enlightenment

Contact: Gwenn Bolt
Title: Teacher/Parent Consultant
Address: 501. S. Boylan Avenue

Raleigh NC 27603

Phone: (919) 856-7774 **Facsimile:** (919) 508-0810

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Early Intervention

OTHER INFORMATION:

Early intervention services for children and families of children are provided. Age range is from birth through kindergarten.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Shigley Family Services

Contact: Scott Bass
Title: Therapist
Address: 3716 National Drive, Suite 124

Raleigh NC 27612

Phone: (919) 783-8846 **Facsimile:** (919) 783-7305

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Counseling services to include:
Individual, Child, and Family
Bereavement Counseling
Child behavior management

OTHER INFORMATION:

A variety of counseling services are provided. Included are family, couple, child and adult individual mental health therapy. Bereavement counseling is also available. We accept insurance reimbursement including Medicaid.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Tammy Lynn Center

Contact: Beth Buch
Title: ECIP Manager
Address: 739 Chappell Drive

Raleigh NC 27606

Phone: (919) 832-3909 **Facsimile:** (919) 832-8475

E-mail:

County: Wake **Primary Client:** Children, ages 0-36 months

SERVICES:

Speech, Physical, and Occupational Therapy
Respite Care
Lending Library for books, toys, and equipment
Case Management

OTHER INFORMATION:

Home based therapy is provided. This includes speech, physical and occupational therapy, and child development. Case management services are also provided. Support group for enrolled families meets monthly for social/educational programs.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Tammy Lynn Center

Contact: Beth Cooper
Title: Family and Infant Specialist
Address: 739 Chappell Drive

Raleigh NC 27606

Phone: (919) 832-3909 **Facsimile:** (919) 832-8475

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Speech, Physical, and Occupational Therapy
Lending Library for books, toys, and equipment
Case Management
Respite Care

OTHER INFORMATION:

Home based therapy is provided. This includes speech, physical and occupational therapy, and child development. Case management services are also provided. Support group for enrolled families meets monthly for social/educational programs.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Teens against AIDS

Contact: Kimberlee Smith
Title: Health Educator/Project Coordinator
Address: St. Augustin's College
1315 Oakwood Ave, Prezell Robinson, Library Rm 207
Raleigh NC 27610

Phone: (919) 516-4344 **Facsimile:** (919) 839-5981

E-mail: STBF-TAA@ix.netcom.com

County: Wake **Primary Client:** Adolescents

SERVICES:

Counseling
Education
Referral to other services

OTHER INFORMATION:

Peer to peer education, counseling, and referral related to HIV/STD/AIDS among minority adolescents

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Triangle Family Services

Contact: Scott Bass
Title: Therapist
Address: 401 Hillsborough Street

Raleigh · NC

Phone: (919) 821-0790 **Facsimile:** (919) 821-1893

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Counseling Services to:
HIV-infected people, their friends, and family

Consumer Credit Counseling
Violence Counseling

OTHER INFORMATION:

The mission of Triangle Family Services is to help people of varying economic means in times of personal stress or crisis by enabling them through counseling, educational, and human services to redirect their lives and strenghten the family.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Triangle Family Services

Contact: Rick Miller-Haraway
Title: Director of Professional Services
Address: 401 Hillsborough Street

Raleigh NC 27603

Phone: (919) 821-0790 **Facsimile:** (919) 821-1893

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Comprehensive Counseling Services to:
HIV-infected people, their friends, and family

Consumer Credit Counseling
Violence Counseling

OTHER INFORMATION:

The mission of Triangle Family Services is to help people of varying economic means in times of personal stress or crisis by enabling them through counseling, educational, and human services to redirect their lives and strenghten the family.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

United Cerebral Palsy

Contact: Lisa Faison
Title: Director
Address: 314 Chapanoko Road

Raleigh NC 27603

Phone: (919) 773-2020 **Facsimile:** (919) 773-1044

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Developmental Day Services
On-site OT, PT, and Speech Therapy

OTHER INFORMATION:

The Charlie Gaddy Center for Children serves children with special needs from birth until 5 years old. Also served are typically developing children with a developmental day program.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Swayzine Archible
Title: Community Social / Service Tech
Address: 10 Sunnybrook Road

Raleigh NC 27620

Phone: (919) 250-3991 **Facsimile:**

E-mail:

County: Wake **Primary Client:** Adults

SERVICES:

Outreach

OTHER INFORMATION:

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Kathy Berkley
Title: SBS Coordinator
Address: 10 Sunnybrook Road

Raleigh NC 27620

Phone: (919) 250-1169 **Facsimile:** (919) 212-7946

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

OTHER INFORMATION:

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Gibbie Harris
Title: Program Manager
Address: P.O. Box 14049

Raleigh NC 27620

Phone: (919) 250-4516 **Facsimile:** (919) 250-4429

E-mail:

County: Wake **Primary Client:** Adults

SERVICES:

HIV Early Intervention
Medical and Primary care for HIV+ individuals
Case Management

OTHER INFORMATION:

Medical evaluation and primary care services for HIV positive individuals are provided regardless of ability to pay. Case management is also available.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Joyce Hill-Wright
Title: Child Service Coordinator
Address: 10 Sunnybrook Road
P.O. Box 14049
Raleigh NC 27601

Phone: (919) 250-4685 **Facsimile:** (919) 250-3984

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Case Management
Healthcare Resources
Developmental Delay Services
Child Service Coordination

OTHER INFORMATION:

Coordinate services for children who are at risk for development delays or who have been diagnosed with developmental delay. Children from birth until five years old are served.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Cindy McDaniel
Title: CSC Program Coordinator
Address: 10 Sunnybrook Road
P.O. Box 14049
Raleigh NC 27601

Phone: (919) 250-4669 **Facsimile:** (919) 212-7946

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Case Management
Healthcare Resources
Developmental Delay Services
Child Service Coordination

OTHER INFORMATION:

Coordinate services for children who are at risk for development delays or who have been diagnosed with developmental delay. Children from birth until five years old are served.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Linda Pace
Title: Child Service Coordinator
Address: P.O. Box 949

Raleigh NC 27602

Phone: (919) 250-4624 **Facsimile:** (919) 250-3984

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Case Management
Healthcare Resources
Developmental Delay Services
Child Service Coordination

OTHER INFORMATION:

Coordinate services for children who are at risk for development delays or who have been diagnosed with developmental delay. Children from birth until five years old are served.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Amy Rigney
Title: HIV/AIDS Case Manager
Address: 10 Sunnybrook Road

Raleigh NC 27620

Phone: (919) 250-4510 **Facsimile:** (919) 250-3999

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Case Management: HIV/AIDS: no charge
HIV counseling and testing services: no charge
Primary care for HIV + adults: sliding scale

OTHER INFORMATION:

Case management is provided for Wake County residents living with HIV /AIDS infection.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Kathy Rowell
Title: Nurse
Address: 10 Sunnybrook Road
P.O. Box 14049
Raleigh NC 27620

Phone: (919) 250-4648 **Facsimile:** (919) 212-7946

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Home Health
Transportation
Coordination with other county agencies

OTHER INFORMATION:

Provides home visits to monitor patient condition, assess status, and monitor medicine compliance. Transportation assistance and service coordination with other agencies in the county are also provided.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Susan Steele
Title: Child Service Coordinator
Address: 10 Sunnybrook Road
P.O. Box 14049
Raleigh NC 27601

Phone: (919) 250-4657 **Facsimile:** (919) 212-7946

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Case Management
Healthcare Resources
Developmental Delay Services
Child Service Coordination

OTHER INFORMATION:

Coordinate services for children who are at risk for development delays or who have been diagnosed with developmental delay. Children from birth until five years old are served.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Health

Contact: Valerie Thomas-Davis
Title: Step by Step Care Coordinator
Address: 10 Sunnybrook Road

Raleigh NC 27620

Phone: (919) 250-1170 **Facsimile:** (919) 212-7946

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Case Management
Medical Treatment
Substance Abuse Treatment

OTHER INFORMATION:

The Step by Step program provides care coordination for pregnant and post-partum women whose lives are impaired by alcohol and drugs. Coordination includes medical and substance abuse problems. Referrals to the program are accepted.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Department of Social Services

Contact: Kenneth Armstrong
Title: CPS Social Work Supervisor
Address: P. O. Box 46833
220 Swinburne Street
Raleigh NC 27620

Phone: (919) 212-7417 **Facsimile:** (919) 212-7450

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Child Protection Services/Treatment

OTHER INFORMATION:

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Medical Center

Contact: James Helm
Title: Child Development Specialist
Address: 3024 New Bern Ave
Suite 307
Raleigh NC [illegible]
Phone: (919) 250-8276 F[illegible]
E-mail:
County: Wake [illegible]

SERVICES:

Developmental Evaluation
Follow-up and Referrals

OTHER INFORMATION:

The Wake County Medical Center provides a Special Infant Care Unit. Developmental evaluations, follow-up, and referrals are also provided. Children aged 0-3 years of age are the primary client.

NOTES:

Project RISK, Multiple Risk associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Mental Health

Contact: Patti Beardsley

Title: Early Intervention Coordinator
Address: 1212 Cedarhurst Drive

Raleigh NC 27609

Phone: (919) 713-9011 Facsimile: (919) 715-7500

Email:
County: Wake Primary Client: Children and Families

SERVICES:

Early Intervention: Children and Toddlers
Case Management
Developmental Assessment
High Risk Intervention

OTHER INFORMATION:

Early intervention services are provided to families with infants and toddlers who are at risk or who are diagnosed with developmental delays.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County MH/DD/SA

Contact: Ilean Hill

Title: Family Consultant
Address: 1212 Cedarhurst Drive

Raleigh NC 27609

Phone: (919) 713-0657 Facsimile: (919) 715-7500

Level:
County: Wake Primary Client: Children & Families

SERVICES:

Early Intervention
Developmental Assessment
Case Management
High Risk Intervention

OTHER INFORMATION:

Early intervention services are provided to families with infants and toddlers at risk for developmental delays or who are diagnosed with developmental delays.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County MH/DD/SA

Contact: Jo Lawson

Title: Substance Abuse Counselor

Address: Step by Step Program
3000 Falstaff Road
Raleigh NC 27610

Phone: (919) 250-1558 Facsimile: (919) 250-1597

Level:

County: Wake Primary Client: Adult

SERVICES:

Case Management
Medical Treatment
Substance Abuse Treatment

OTHER INFORMATION:

The Step by Step program provides care coordination for pregnant and post-partum women whose lives are impaired by alcohol and drugs. Coordination includes medical and substance abuse problems. Referrals to the program are accepted.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County MH/DD/SA

Contact: Warren Ludwig
Title: Director of Children's Services
Address: 2321 Crabtree Blvd

Raleigh NC 27604

Phone: (919) 856-5300 **Facsimile:** (919) 856-5321

E-mail:

County: Wake **Primary Client:** Children

SERVICES:

Mental Health/Sub. Abuse Assessment
Mental Health/Sub. Abuse Treatment

OTHER INFORMATION:

Mental health and substance abuse assessment are provided. Treatment is also provided for the individual, including children and adolescents, and their families.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County MH/DD/SA

Contact: Linda Roberts
Title: CSAC
Address: 3000 Falstaff Road

Raleigh NC 27610

Phone: (919) 250-1540 **Facsimile:** (919) 250-1597

E-mail:

County: Wake **Primary Client:** Adults

SERVICES:

Substance abuse services

OTHER INFORMATION:

Inpatient, outpatient, and day treatment substance abuse services are provided.

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County MH/DD/SA

Contact: Margaret Stitt
Title: Director of Nursing
Address: 3000 Falstaff Road

Raleigh NC 27620

Phone: (919) 250-1547 **Facsimile:** (919) 250-1597

E-mail:

County: Wake **Primary Client:** Children & Adults

SERVICES:

Mental Health/Sub. Abuse

OTHER INFORMATION:

Mental Health and Substance Abuse services

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Wake County Preschool Services

Contact: Betsy Allen
Title: School Social Worker
Address: 2302 Noble Road

Raleigh NC

Phone: (919) 856-2955

E-mail:

County: Wake

SERVICES:

Pre-School/After-School

OTHER INFORMATION:

Provide support to families who have have preschool children with disabilities. Also have a lending library with information on HIV/AIDS.

NOTES:

Project RISK, Multiple Risk
U.S. Department

Wake County Public Schools

Contact: Carolyn Hammond
Title: Pre-School Case Manager
Address: P.O. Box 28041

[redacted]

SERVICES:

None Listed

OTHER INFORMATION:

None Listed

NOTES:

[redacted]

Wake Medical Center - Special Infant Care Clinic

Contact: Melissa Johnson
Title: Psychologist
Address: 307 New Bern Ave, Suite 307

[redacted]

SERVICES:

Child Development
Medical and Developmental Follow-up
Nutrition Services / Feeding Specialist
Pediatric Physical Therapy
Speech Pathology

OTHER INFORMATION:

The clinic staffs a variety of professionals who specialize in developmental follow-up. Professionals include a neonatologist, physchologist, pediatric physical therapist, and others. Nutrition services and immunizations are also available.

NOTES:

[redacted]

Additional page for your contacts

Contact:
Title:
Address:

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

OTHER INFORMATION:

NOTES:

[redacted]

Additional page for your contacts

Contact:
Title:
Address:

Phone: **Facsimile:**

E-mail:

County: **Primary Client:**

SERVICES:

OTHER INFORMATION:

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Additional page for your contacts

Contact:
Title:
Address:

Phone: **Facsimile:**

E-mail:

County: **Primary Client:**

SERVICES:

OTHER INFORMATION:

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Additional page for your contacts

Contact:
Title:
Address:

Phone: **Facsimile:**

E-mail:

County: **Primary Client:**

SERVICES:

OTHER INFORMATION:

NOTES:

Project RISK, Multiple Risk Associated with Prenatal HIV, funded by the U.S. Department of Education #HO24B30012.

Meetimg Roster from Surry County

Surry County AIDS Luncheon Roster

Wake Forest University Baptist Medical Center

Ms. Barbara Anderson
Social Work Program Manager
Surry Co. Dept. of Social Services
118 Hamby Road
Dobson NC 27017

Work Phone: (336) 401-8800
Fax Number: (336) 401-8860
Email Address:

Area of Service: Adults & Children

Ms. Tabitha Atkins
Social Worker
Surry County Department of Social Services
118 Hamby Road
[illegible]

Work Phone: (336) 401-8800
Fax Number:
Email Address:

Area of Service: Children

Ms. Lenora Bassett
Social Worker II
Surry County Department of Social Services
118 Hamby Road
Dobson NC 27017

Work Phone: (336) 401-8800
Fax Number: (336) 401-8860
Email Address:

Area of Service: Children

Ms. Misty Bellard
Social Worker
Surry County Department of Social Services
118 Hamby Road
Dobson NC 27017

Work Phone: (336) 401-8800
Fax Number: (336) 401-8860
Email Address:

Area of Service: Children

Ms. Alison Bledsoe
Social Worker
Surry County Department of Social Services
118 Hamby Road
Dobson NC 27017

Work Phone: (336) 401-8800
Fax Number: (336) 401-8860
Email Address:

Area of Service: Children

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Surry County AIDS Luncheon Roster

Wake Forest University Baptist Medical Center

Ms. Debbie Bowman
Social Work Supervisor
Surry Co. Dept. of Social Services
118 Hamby Road
Dobson NC 27017

Work Phone: (336) 401-8800
Fax Number: (336) 401-8660
Email Address:

Area of Service: Adults & Children

Mr. Sam Bowman
Surry SCAN
215 Jones School Road
Mt. Airy NC 27030

Work Phone: (336) 786-1080
Fax Number: (336) 786-1080
Email Address:

Area of Service: Children

Ms. Susie Branch
MSSW
Surry County Health and Nutrition Center
[illegible]
Dobson NC 27017

Work Phone: (336) 401-8400
Fax Number:
Email Address:

Area of Service: Children

Mr. Allen Simmons
Medical Associates of Surry
965 Westlake Dr.
Mt. Airy NC 27030

Work Phone: (336) 719-4108
Fax Number:
Email Address:

Area of Service: Adults

Rev. Beth Brittain
Director of Support Services/Chaplain
Hospice of Surry County, Inc.
1326 North Main Street
Mt. Airy NC 27030

Work Phone: (336) 789-2922
Fax Number: (336) 789-0856
Email Address:

Area of Service: Adults & Children

Surry County AIDS Luncheon Roster

Wake Forest University Baptist Medical Center

Ms. Beverly Brooks
Medical Social Worker
Northern Hospital of Surry County
PO Box 1101
Mt. Airy NC 27030

Work Phone (336) 719-7000
Fax Number (336) 719-7484
Email Address

Area of Service Adults

Ms. Stephanie Brooks
Executive Director
Children's Center of Surry, Inc.
PO Box 692
Dobson NC 27017

Work Phone (336) 386-9144
Fax Number
Email Address

Area of Service Children

Ms. Rebecca Carter
Coordinator
Surry Domestic Violence Program
Post Office Box 71
Mt. Airy NC 27030

Work Phone (336) 786-6155
Fax Number (336) 786-1957
Email Address

Area of Service Adult & Children

Ms. Marie Conner

Work Phone (336) 786-1365
Fax Number (336) 786-1365
Email Address

Surry SCAN
215 Jones School Road
Mt. Airy NC 27030

Area of Service Children

Ms. Patricia Coe
MCC/SW
Surry County Health and Nutrition Center
118 Hamby Road
Dobson NC 27017

Work Phone (336) 401-8400
Fax Number
Email Address

Area of Service Children

Slides from Community Meetings

The Changing Epidemiology of HIV in Children

HIV in the U.S.

Most rapidly growing group?	**Women**
Region?	**South**
Urban versus rural areas?	**Rural**

HIV in Children in the U.S.

>92% acquired perinatally

ACTG 076 results (NEJM, 1994)

with Zidovudine (ZDV; AZT)
transmission reduced from 25.5% to 8.3%

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The Changing Epidemiology of HIV in Children

Changing numbers of infants with HIV infection

	1993	1994
Infected	21%	8.5%
Not infected	79%	91.5%

Why the epidemiological shift?

75% of the women identified in pregnancy took ZDV

Mothers who took ZDV: 5.7% transmission

Mothers who did not take ZDV: 13.9% transmission

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The Changing Epidemiology of HIV in Children

Identification of infant HIV status

75% with HIV are identified by 3 months

Of 100 infants born to women with HIV
97 will be identified during pregnancy

75 will take ZDV to prevent transmission

5 + 4 = approximately 9 infants HIV+

86 infants will be HIV+ - but at multiple other risks for non optimal behavioral and developmental outcomes

They are eligible for services but we have to get them to services

The Changing Epidemiology of HIV in Children

Identification in pregnancy in North Carolina

Prevalence- Seropositivity study at delivery

1990 to 1994
881 infants born to 877 HIV+ women

e.g., 1.6 to 2.3/1,000 deliveries

Toward identification during pregnancy

1993	1994
63%	97%

Project RISK

- A demonstration of a model for transition from tertiary hospital care to community services for children with Multiple Developmental Risks Associated with Maternal HIV Infection.

Child and Family

TERTIARY CARE ⟶ **HOME COMMUNITY**

- Diagnosis
- Assess needs of child and family
- Facilitate access to services in community

- Assess needs and services
- Engage with family
- Coordinate services

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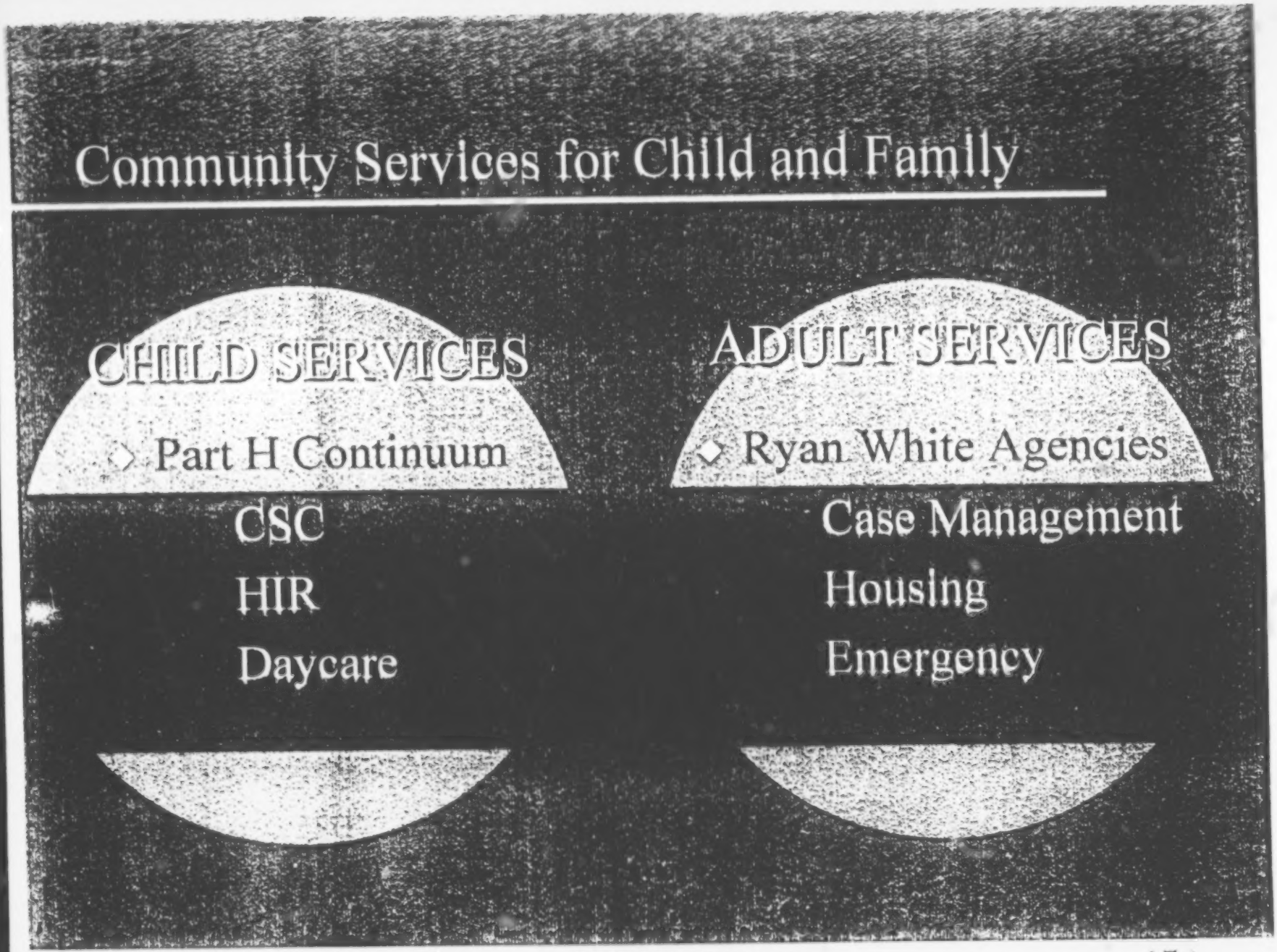

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Maternal Social Isolation/Support
Items from the Maternal Social Support Inventory

Number of people who could babysit in case of an emergency?

None	50%
One person	44%
More than one	6%

People to talk to (psychological support)

None	22%
Yes, but not happy with	9%
Yes, and happy with	69%

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Maternal Health Needs

Self-reported symptoms
(sample from Bowman-Gray replication site on n=10)

Results:	Subscale	% Cases
	Psychoticism	50%
	Depression	33%
	Global symptoms	60%

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Child development at 1 year

Needs for child services coordination and/or early intervention

The Bayley Scales of Infant Development (1969, 1993)

Results:

Mental development (MDI) (n=32)

Mean= 90.9 (16)
Median= 94.5

% <85= 31.2
% <70= 16 (5 children; 1<50)

Motor development (PDI) (n=32)

Mean= 85.0 (19.4)
Median=89.5

% <85= 43.7%
% <70= 21.9% (7 children; 4 <50)

What do families say they need? The Family Needs Questionnaire

• Information about child's condition	54%
• Information about services for child	62%
• Help paying for food	49%
• Would like counselor, psychologist	3%
• Family needs support	25%
• Family needs help discussing problems	3%

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Referrals resulting in service utilization at transition from hospital to community care (examples)

Child Services	
Child services coordination	83%
Early Intervention	50%
Developmental evaluation centers	40%
Respite care	12.5%
Adult/family services	
HIV consortium (Ryan White)	86%
Support group	33%
Mental health/substance abuse	37.5%

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Key Respondents

- N=42 community providers
- Child Service Coordinators=14
- Early Childhood Interventionists=9
- Substance Abuse Providers=12
- Other=7

Bad News

- < 20% of Child Providers made frequent referrals to support groups
- < 15% of CSC's identified a substance abuse counselor
- < 20% of Child Providers identified an *adult* mental health professional

A Little More Bad News

- < 25% of Adult Providers referred to Child Providers
- Adult Providers made no referrals to CSC
- < 10% of Adult Providers identified medical providers in the community

The Last of the Bad News

- < 50% of Adult and Child Providers identified a DSS worker
- Virtually no Adult and Child Providers knew of the HIV Consortium

More Good News

- All Adult Providers who referred to support groups (60%) referred on a frequent basis
- 60% of Adult Providers referred clients to transportation services
- 90% of Adult Providers identified other adult and child mental health professionals

Good News

- 90% of Child Providers referred to Child Services
- 90% of Child Providers identified other Child Providers
- > 70% of Child Providers identified community medical providers
- > 75% of Child Providers referred to financial entitlement programs
- Almost 70% of Child Providers referred clients to legal services

And More Good News!!

- 80% of Adult and Child Providers referred to DSS
- > 80% of Adult and Child Providers referred to child care
- > 75% of Adult and Child Providers referred to MH/SA services
- > 90% of Adult and Child Providers identified *child* mental health professionals

Duke Informed Consent

CONSENT FOR RESEARCH

RISK ASSOCIATED WITH PRENATAL HIV EXPOSURE DEMONSTRATION MODEL

IRB PROTOCOL #: 1209-94-9

We are asking you to take part in a project in the department of Pediatrics at Duke University Medical Center. The nature of the project, risks, inconveniences, discomforts, and other information about the study are discussed below.

The purpose of the project is to provide family centered, community-based care for you and your baby. The project is designed to provide direct services such as the assessment of family needs and infant development as well as community linkages with needed services. This project may make it easier for you and your baby to get the services you need and also improve the quality of those services. All information will be shared and discussed with you.

There are two major components to the project:

I. Direct Services: Interdisciplinary assessments of infant development and family support needs are offered after your first visit to the Pediatric Infectious Disease Clinic. These assessments include discussing your family's and baby's needs with other team members as well as our interviews with you.

II. Community Linkages: Once family needs are identified, linkages with services in your home community will be made. The diagnosis will not be shared with community agencies unless you provide a release of information specific to HIV infection. Permission will be obtained from you before each community referral is made

All interviews will take place at the Pediatric Infectious Disease Clinic during a regularly scheduled clinic visit. Follow-up phone calls may be necessary. The interviews should not take more than 40 minutes of your time.

All information regarding child and family needs and community linkages will be confidential and will kept in a research chart for your baby.

_____

Parent (guardian) initials

CONSENT FOR RESEARCH

RISK ASSOCIATED WITH PRENATAL HIV EXPOSURE DEMONSTRATION MODEL

Information in the research chart is protected from criminal and/or civil actions under the Federal Law 42CFR. Only a court order from a judge will force us to share the information obtained from project records with an attorney or social agency. As in all situations, we are obligated by law to report cases of suspected child abuse and/or neglect. Your project records, however, will continue to be protected from criminal and/or civil prosecution as described above.

You may refuse to participate or withdraw from this project at any time without interfering with your or your baby's regular medical treatment. There will be no charge to you for evaluations or procedures associated with this project.

Benefits related to participating in this project include improved access to community resources as well as improvement in the quality of services. Risks or inconveniences include being interviewed about personal matters and filling out a questionnaire.

Finally, you should be aware that immediate necessary care is available if any individual is injured because of participation in a research project. However, there is not provision for free medical care or monetary compensation for such injury.

"I have read the above and agree to my participation and that of my baby's as volunteers. I understand that I may contact Dr. Karen O'Donnell or Cindy Fair at 684-5513 with any questions. I further understand that I may contact the Risk Management Office (684-3277) with any questions concerning my child's rights as a participant in a project."

_____ _____

Date Signature of parent (guardian)

_____ _____

Date Signature of individual obtaining consent

Evaluation for Community Meetings

Community Luncheon Evaluation

County(ies) served by agency _____

1. Who are your primary clients?

____ Children

____ Adolescents

____ Adults

____ Combination of above (Please specify) _____

2. What aspects of the luncheon did you find most useful?

3. What aspects of the luncheon did you find least useful?

4. How could the luncheon be improved?

5. Who is the most important person you met today?
(Please don't give specific name just job title.)

6. Any additional comments?

Care providers' view of family community needs

Name_____

Care providers' view of family community needs

- **Practitioners (MD, PNP, PA)**
  - No needs at this time
  - Local provider
  - PT/OT
  - Nutrition
  - Home health
  - Public health nursing
  - Hospice
  - Other _____

Additional Comments

- **Social work**
  - No needs at this time
  - Transportation
  - Hospice
  - Mental health services
  - Shelter (homeless/battered women)
  - Substance abuse tx.
  - Respite care
  - Housing
  - Parenting classes
  - Assistance obtaining income related services (Medicaid, AFDC, SSI)
  - Day care
  - Foster care
  - Other _____

Additional Comments

- **Neuropsych**
  - No needs at this time
  - DEC referral
  - PACT team
  - OT/PT
  - Speech/hearing
  - Daycare/Headstart
  - CSC
  - Mental health services
  - Other _____

Additional Comments

- **Pharmacy**
  - No needs at this time
  - Home health
  - Other _____

Additional Comments

- **Substance Abuse**
  - No needs at this time
  - Outpatient treatment
  - Inpatient treatment
  - Residential treatment
  - Other _____

Additional Comments

Community Service Family Plan

Community Service Family Plan

Child's Name _____
Caregiver's Name _____
Description of family needs to be addressed by community services

Agency Contacted	Phone #	Contact Person	Need to be addressed	Outcome of Contact

Necessary Follow-up